

# Development and Evaluation of the Person Attuned Musical Interaction (PAMI) in dementia manual- UK version

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#### Foreword

At the time of the thesis submission and Viva, the intervention described in this thesis was called PAMI-UK, with the original PAMI being referred to as PAMI-DK. Since the submission, there has been further discussion with the Danish PAMI team and further development of the PAMI interventions in the two countries. We have agreed that the intervention developed during this PhD studentship will be called PAMI-Modified (PAMI-M), with the original PAMI being referred to as PAMI. The intervention has been referred to as PAMI-UK in the thesis throughout to maintain consistency, but future publications will refer to the intervention as PAMI-M.

## Abstract

**Background**- People living with dementia in care homes often have difficulty communicating. Person Attuned Musical Interaction (PAMI) is a music therapy skillsharing training tool originally developed in Denmark that aims to raise staff's awareness of musical interactions to encourage them to use communication forms that remain accessible to residents with dementia. This study aimed to translate and adapt PAMI for the UK, before evaluating the adapted intervention in UK care homes.

**Methods** – A narrative synthesis systematic review investigated how care home music interventions facilitate social interactions. The results, along with expert consultations with care staff and the Danish team, guided the cultural adaptation of PAMI-UK. PAMI-UK consists of a 3-hour online training webinar, a manual, and fortnightly reflective sessions. For the manual field-testing study five staff-resident dyads from three care homes participated, with PAMI-UK implemented for eight weeks. The manual evaluation study included 19 dyads from four care homes, with PAMI-UK implemented for 18 weeks. Qualitative data included diary entries, postintervention interviews, reflective session transcripts and resident questionnaires. The evaluation study additionally collected quantitative data using SCIDS, QUALIDEM, MiDAS and M-NCAS. The studies explored the suitability, usability and readability of PAMI-UK and the impact the intervention had on staff and residents. Results - The final PAMI-UK intervention consists of four elements: The Voice explores the musical parameters within the voice including tempo, pitch, and volume. Framing focuses on assessing and altering the care home environment in relation to sounds. Balancing explores resident's and staff's arousal and emotional state. Connecting focuses on using music to create meaning interactions. Resulting from the systematic review and expert consultations, the course layout, duration, and training facilitator was altered. Rather than the intervention training music therapists to train care staff, PAMI-UK was culturally adapted for the PAMI-UK team to train care staff directly. The manual field-testing and evaluation studies demonstrated staff successfully implementing all four PAMI-UK elements adapting skills to resident's needs. Although the manual was well received by staff, the field-

testing study highlighted several key areas requiring refinement including providing information on using PAMI-UK in group situations, creating a recap sheet, and reflective prompt sheets. The qualitative analysis showed that staff altered their behaviour, and subsequently, resident behaviour changed. Both staff and residents reported being happier, less stressed, and calmer, which had a positive impact on the care home environment and subsequently improved task efficiency. SCIDS score increased (P=0.04), suggesting that staff felt more competent in caring for residents with dementia. Residents' tense behaviour also improved (P=0.03).

**Conclusion** - The systematic review, staff consultations, and discussions with the Danish team ensured that the manual was suitable for UK care homes whilst aligning with the original principals and components. PAMI promotes the embedding of person-centred care into residents' daily lives through music interactions, making residents equal communication partners regardless of their language abilities. Staff demonstrated the development of 'doing with' relationships built on independence and the person behind the dementia diagnosis. Both care home studies had high dropout rates and missing data due to the researchers being unable to attend care homes owing to COVID-19 restrictions. The training was delivered remotely to adhere to the COVID-19 guidelines; however, this made it difficult to determine whether the intervention was implemented correctly. Future research is needed that addresses the methodology difficulties such as online delivery, high dropout rates, and lack of persons with dementia perspective. PAMI-UK has the potential to change care home culture, which future studies should explore.

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## Declaration

No part of this thesis has been submitted in support of an application for any other academic degree or qualification at the University of Nottingham or any other academic institution.

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## Abbreviations

ADL- Activities of Daily Living

BPSD- Behavioural and Psychological Symptoms of Dementia

CST- Cognitive Stimulation Therapy

COVID-19- Coronavirus 19

CQC- Care Quality Commission

DSM- Diagnostic and statistical Manual of Mental Disorders

DSRS- Dementia Severity Rating Scale

EIHR- National Institute for Health Research

**ENRICH- Enabling Research In Care Homes** 

FMAP- Formative Method for Adapting Psychotherapy

**GDP- Gross Domestic Product** 

**GDPR-** General Data Protection Regulation

HCPC- Health and Care Professions Council

- ICD-11- International Classification of Diseases Version 11
- IMH- Institute of Mental Health
- IMMC- Integrated Model of Music Care

Low-fi- Low Fidelity

LSP- Lego Serious Play

MiDAS- Music in Dementia Assessment Scale

M-NCAS- Modified Nursing Care Assessment Scale

- MRC- Medical Research Council
- MTC- Music Therapeutic Care
- NHS- National Health Service
- NICE- National Institute for Heath and Care Excellence

PAMI- Person Attuned Musical Interaction

- PAMI-DK- Person Attuned Musical Interaction- Danish Version
- PAMI-UK- Person Attuned Musical Interaction- United Kingdom Version
- PCTB- Professional Care Team Burden
- PDF-Portable Document Format
- PI- Principal Investigator
- **PPE-** Personal Protection Equipment
- PPI- Public and Patient Involvement
- PRISMA- Preferred Reporting Items for Systematic Reviews and Meta-analyses
- **RCT-** Randomised Control Trial
- SCIDS- Sense of Competence In Dementia Scale
- SD- Standard Deviation
- UK- United Kingdom
- USA- United States of America
- **UTI-** Urinary Tract Infections
- VAS- Visual Analogue Scales
- VIPS- Very important persons
- WW2- World War 2

## Contributors mentioned in this thesis

- BS- Brigette Schneible- Music Therapist and researcher, Drexel university, USA
- BW- Bryony Waters- PAMI-UK PhD Researcher
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- OM- Orii McDermott- Music Therapist and PAMI-UK PI

RF- Rachael Fothergill- Care Home In Reach, Clinical Research Practitioner, Lincolnshire Partnership NHS Foundation Trust

## Published Papers and Presentations

- Waters, B., Orrell, M., & McDermott, O. (2022). The development of a UK culturally adapted version of the Person Attuned Musical Interaction (PAMI) manual: protocol for a two-phase mixed method study. *JMIR Research Protocols*. 21(1). https://doi.org/10.2196/43408
- Waters, B., Sousa, L., Orrell, M., & McDermott, O. (2022). Analysing the use of music to facilitate social interaction in care home residents with dementia: Narrative synthesis systematic review. *Dementia Journal*, *21*(6), 1–23. https://doi.org/10.1177/1471301222110062
- Waters, B., McDermott, O. & Ridder, H.M.O. (2022, June 8-12th). Development of Person Attuned Musical Interaction UK version (PAMI-UK): Online training for care home staff working with people with dementia [Poster presentation]. The 12<sup>th</sup> European Music Therapy Conference, Edinburgh, UK
- Waters, B., Orrell, M. & McDermott, O. (2022, October 17-19<sup>th</sup>). Person Attuned Musical Interaction (PAMI) in Dementia Manual- UK Version [Oral Presentation]. The 32<sup>nd</sup> Alzheimer Europe Conference, Bucharest, Romania
- Waters, B., Orrell, M. & McDermott, O. (2022, October 30<sup>th</sup>). Person Attuned Musical Interaction (PAMI)- UK Version [Oral Presentation]. The Music Therapy Charity Conference, London, UK
- Waters, B., Orrell, M. & McDermott, O. (2023, October 16-18<sup>th</sup>). Culturally adapting the Person Attuned Musical Interaction (PAMI) manual to be suitable for UK care homes [Poster Presentation]. Helsinki, UK
- Waters, B., Orrell, M & McDermott, O. (2023, October 16-18<sup>th</sup>). The evaluation of the person Attuned Musical Interactions (PAMI) in Dementia Manual- Light version [Poster Presentation]. Helsinki, UK

## 1. Introduction

#### 1.1 Dementia

#### 1.1.1 Definition and Prevalence

The advances in technology, medicine, and education in the 20<sup>th</sup> and 21<sup>st</sup> centuries have decreased early mortality rates and increased life span (World Health Organisation and Alzheimer's Disease International, 2012). Although in developed countries living over 65 is long established, the life expectancy in developing countries has also increased, making the ageing population a global trend (Lloyd-Sherlock, 2004, P1). One consequence of the ageing population is the increasing trend in diseases and conditions generally observed more in older ages, such as dementia (Prince et al., 2007; World Health Organisation, 2019).

Dementia is a syndrome encompassing over 100 degenerative and progressive diseases (Lindsay, 2008; National Institute of Health and Care Excellence, 2018; Ridder, 2003). The International Classification of Diseases (ICD-11) categorises dementia as an acquired brain syndrome characterised by a decline in cognitive function, which is not entirely attributed to normal ageing (World Health Organisation, 2019). The cognitive decline must affect the individual's ability to complete Activities of Daily Living (ADL). The most common dementia types are Alzheimer's disease (60-80%), Vascular Dementia (17-40%), Dementia with Lewy Bodies (4-10%) and Frontotemporal Dementia (2%) (Alzheimer's Association, 2020a; Gaugler et al., 2016; Lee, 2011; Prince et al., 2014). Whilst dementia is predominantly diagnosed in adults over 65, it can develop at any age. From age 30 to 95, prevalence rates double every five years (Prince et al., 2007). In those over 65's, there is a one in 14 prevalence rate, which increases to one in six in over 80's. In 2019, 55 million individuals worldwide were diagnosed with dementia, with expected prevalence to increase to 78 million by 2030 and 139 million by 2050 (World Health Organisation, 2021). Currently, most dementia diseases are incurable (Jalbert et al., 2008). The prevalence rates and incurability makes dementia a public health concern that significantly impacts individuals, families, communities, and the economy (Young Dementia UK, 2021).

#### 1.1.2 Symptoms of Dementia

Dementia is characterised by a decline in cognitive function that impairs daily living. A dementia diagnosis requires a decline in two or more cognitive functions, which cause impairments, excluding alertness or attention (Oh & Rabins, 2019).

Although common symptoms exist that indicate dementia, factors including affected brain areas, lifestyle, personality, environmental factors, other health conditions, dementia type and dementia severity result in variations in symptoms between individuals. The symptoms can be categorised into cognitive and psychological changes. Cognitive symptoms include memory loss, visual and spatial impairments, problem-solving impairments, confusion, and disorientation. The cognitive symptoms have previously been referred to as the 7 As' (Puxty et al., 2009) (Table 1.1), particularly on carers' support websites.

Symptom		Description	Behaviours explained	
Anosognosia	Lack of knowledge of the illness	The individual lacks knowledge of their impairments. They have difficulty accepting change in their ability and need extra support and assistance.	<ul> <li>Poor judgment</li> <li>Poor problem-solving and planning</li> <li>Overestimation of abilities</li> <li>Unaware that they are in hospital or a long-term care home</li> </ul>	
Amnesia	Loss in memory	Individuals do not have access to long-term memory, meaning they are no longer consciously learning. They start to forget most recently stored memories, leading to individuals only accessing earlier memories. Therefore, they can believe they are still living in that time.	<ul> <li>Anxiety caused due to information overload</li> <li>Accusing family members of things</li> <li>Unable to remember how to complete familian tasks</li> <li>Repeating questions or behaviours</li> </ul>	
Aphasia	Loss of language	Individuals may be able to express themselves but unable to understand others' communication. Alternatively, they may be able to understand others' communication but unable to express themselves.	<ul> <li>Communication difficulties</li> <li>Misunderstanding between individuals</li> <li>Social isolation and withdrawal</li> <li>Word substitution</li> <li>Revert to their first language if bilingual</li> </ul>	
Agnosia	Loss of recognition	Individuals are unable to recognise and respond appropriately to stimuli. The stimuli can be visual, auditory, or somatosensory.	<ul> <li>Do not recognise family members and friends</li> <li>Do not recognise themselves in the mirror, which causes anxiety</li> <li>Believe that they are still at a younger age</li> <li>Inappropriate sexual behaviour</li> </ul>	

#### Table 1.1 The 7 As' of Dementia (Puxty et al., 2009)

			<ul> <li>Inappropriate use of objects</li> </ul>
Apraxia	Loss of purposeful movement	Individuals cannot plan and execute a task's steps in the correct order.	<ul> <li>Inability to coordinate movement for a task such as dressing</li> <li>Shift from task due to being easily distracted</li> <li>Agitation and frustration are experienced wher the individual feels the task is too challenging</li> </ul>
Altered Perception	Loss of visual perception	A change in the way an individual views the environment. They may experience visual distortions.	<ul> <li>Resistance to bathing due to the inability to judge the depth of water</li> <li>Jumping over dark thresholds or flooring as they believe it is a hole</li> <li>Avoid flooring with bold patterns</li> <li>Misinterpret objects, might not see a person sitting on a chair</li> <li>Believe people on television are in the room</li> </ul>
Apathy	Loss of initiation	An individual experiences the inability to initiate communication or activities.	<ul> <li>Will not eat food in front of them unless instructed</li> <li>Can spend most of the day in silence unless someone starts the conversation</li> </ul>

Although the classification of dementia in the ICD or Diagnostic and Statistical Manual of Mental Disorders (DSM) does not identify psychological and behavioural elements of dementia as a defining feature, their assessment is critical (Cerejeira et al., 2012). Assessing psychological and behavioural symptoms can aid in identifying dementia type and treatment decisions (Cerejeira et al., 2012; McKeith & Cummings, 2005). Behavioural and Psychological Symptoms of Dementia (BPSD) or neuropsychiatric symptoms (Table 1.2) consist of a cluster of heterogeneous noncognitive symptoms and behaviours (Lawlor, 2018). Similar to cognitive symptoms the BPSDs experienced, severity and onset vary between individuals. BPSDs significantly impact both the individual with the diagnosis and caregivers due to increased cognitive decline, greater risk of falls, increased carers burden, earlier institutionalisation, increased medication use, and decreased quality of life for the individual with dementia and their caregivers (Finkel, 2000). Nearly all individuals with dementia will experience one or more BPSD during the condition. Prevalence rates vary between studies, but around two-thirds of individuals with dementia experience one or more BPSDs (Devshi et al., 2015). Unlike cognitive symptoms, which progressively decline, BPSDs fluctuate episodically, with the timing of symptoms being unpredictable (Kales et al., 2015).

Dementia is broadly referred to in three stages, mild, moderate, and severe. As mentioned previously, the symptoms and progression vary between individuals (Finkel, 2003; Lawlor, 2018 Kales et al., 2015). The BPSDs may develop and then reduce or disappear at later stages or vary daily, making it challenging to assign individuals to the stages exactly. Nonetheless, the stages give an overview of what may be expected as the condition progresses and worsen.

Table 1.2 Behaviour and psychological symptoms of dementia (Finkel, 2003; Kales et al., 2015)

#### Symptoms

Delusions

Hallucinations

#### Agitation

-Shouting or screaming

- Verbal abuse
- Physical abuse (kicking, punching)
- Resistance to care

Aggression

Depression

Anxiety

Apathy

Disinhibition

Irritability

Affective lability

#### Restlessness

- Wandering
- Pacing
- Fidgeting

Sleep disturbance

-Sleeplessness

-Night-time waking

Shadowing

## 1.2 Sociological models of dementia

Dementia is predominantly situated within the biomedical model, which reduces the individual to their symptoms, disregarding their identity and other attributes (Fazio et al., 2018; Milne, 2020). Viewing dementia through the Biomedical model results in an emphasis placed on an individual's difficulties and deficits rather than their

capabilities. Meaningful actions can be reduced to products of symptoms, leading to certain behaviours being coined 'problematic' rather than being observed as justified behaviours in relation to the situation or as a form of communication (Beard, 2004; Cohen-Mansfield, 2000). Reducing individuals to their symptoms dehumanises and depersonalises them, resulting in the stigmatisation and discrimination within the media, the public's perception, services, and policies (Higgs & Gilleard, 2017; Nolan et al., 2006; Nguyen et al., 2020). Individuals with dementia have been viewed as living without mind, losing oneself and referred to as a living death, raising debates around the rights of individuals with dementia (Jellinger, 2010). These views are rooted within the field, with the word dementia coming from the Latin 'demens', meaning 'out of mind'. Therefore, there is a long-standing perception that will take time to change. Viewing individuals with dementia as losing their identity and self creates the perception of them being different to the rest of society (Naue & Kroll, 2009). The concept of 'otherness' creates a divide between 'Us' and 'Them', which can lead to people with dementia being treated as less of an adult human and instead treated like a child, animals, inanimate objects or as if they were dead (Naue & Kroll, 2009; Speering & Speering, 2021).

While people with dementia can be perceived as 'other' at the same time, people without dementia can also identify with the 'other', creating high levels of fear and anxiety around their own ageing (Naue & Kroll, 2009). Research has suggested that the fear of dementia can relate to the loss of control and awareness, behavioural changes, concerns about not recognising family members, the loss of independence and fear of being a burden. In the early stages of dementia, the fear and anxiety surrounding dementia increase as a result of concerns about the unknown progression of the condition, the fear of future losses and the reaction of others to their diagnosis (Riley et al, 2014).

Individuals with dementia can experience negativity from others when disclosing their dementia diagnosis with the negative stereotypes and societal attitudes experienced by some, leading to the person with dementia feeling negative about

themselves, which negatively impacts their identity (Riley et al., 2014). The word dementia evokes preconceived ideas and misconceptions which can be placed on the individual with dementia before there is time to understand the subjective experience of the individual, leading to the stigmatisation of dementia that is experienced in society (Reed & Bluethmann, 2009). The negative response from others can lead to individuals choosing not to disclose their diagnosis to friends, family, and employers as they feel ashamed, leading to them withdrawing from society to hide the signs of dementia (Riley et al., 2014).

As mentioned previously, the changes in an individual's behaviour result in those with dementia being perceived as losing their identity and sense of self. It is argued that a sense of self is vital for humans as it means that we know that we are, who we are, are proud of our abilities, and feel respected by others (Norborg, 2019). While many individuals can be confident they have a sense of self, it is questioned whether people with dementia can achieve these concepts partly due to dementia symptoms and partly due to others' perceptions of dementia. If one loses their sense of self, this creates the assumptions of loss of agency and citizenship status that can lead to debates around the human rights of a person with dementia (Kontos et al., 2017). However, there is no consensus on whether the self is preserved during dementia. Sabat & Harre (1992) proposes that each individual has three selves. Self 1 is the self of personal identity that expresses our embodied experience as a singular continuous person located in space, time, and local moral order. This self is manifested when we speak in the first person. Self 2 concerns how we perceive ourselves in the moment and our beliefs about our physical and mental attributes, such as height, weight, and educational achievement. Some of these attributes are unchangeable, while others will alter throughout life. Self 3 is the social personnel, which is how we present self 1 and 2 to others; this self changes depending on the situation and the other person's perception. It has been argued that aspects of the self can be and must be preserved in people with dementia as they can assess internal states such as feeling cold and pain, and moments of lucidity would be challenging to explain if the self was lost entirely (Norbog, 2019). However, to

preserve the sense of self, the individual may rely on the support of others. Self 1 is unchangeable; however, self 2 and 3 can be impacted by the condition's progression. The impact on self 2 and 3 can be limited with support from others, such as making the individual feel seen and heard, providing opportunities for the individual to use their abilities, and ensuring the person feels proud, loved, and acknowledged.

Slowly society is moving away from positioning dementia solely in the Biomedical model, with several sociological approaches being proposed in an attempt to reframe dementia and the experience of individuals with a diagnosis (Milne, 2020). Kitwood is a crucial researcher in changing the societal views of dementia with his proposed approaches of malignant social psychology, personhood, and personcentred care (Kitwood, 1997). As mentioned previously, other people's attitudes and views significantly impact an individual with dementia, by the loss experienced being amplified, leading to the reinforcement of depersonalisation resulting in them being ignored, dismissed, and marginalised. Kitwood introduced personhood and personcentred care to humanise people with dementia, focusing on the subjective experience of each individual to determine their care and treatment.

#### 1.2.1 Kitwood's Person-centred Care and Personhood

Human experiences are subjective; individuals have different emotions, preferences, and needs (Kitwood,1997), this subjectivity remains after a diagnosis of dementia. Not only will individuals' dementia symptoms and experiences differ from others, but their life history, preferences, and needs also differ. Person-centred care recognises the individual's subjectivity, acknowledging their impairments, abilities, and the person behind the diagnosis (Kitwood, 1997). The theory aims to recognise the message behind behaviours or communication that seem nonsensical. Personcentred care also acknowledges that the care for an individual with complex conditions should be multi-disciplinary. Teams should include healthcare professionals, family members, and the individual with dementia, with the individuals being active partners in their care and treatment decisions (Coulter & Oldham, 2016).

Care provided should be cooperative and reciprocal rather than done 'to' or 'for' the person (Kitwood, 1993). Care should be tailored to individual with their preferences, needs, and beliefs taken into account to maintain their identity and personhood. Personhood is "a standing or status bestowed upon one human being, by others, in the context of relationships and social being. It implies recognition, respect, and trust" (Kitwood, 1997, P8). Personhood is vital for society and carries ethical connotations; certain rights exist for a person, including the right to respect and privacy (Kitwood & Bredin, 1992). When viewing individuals with dementia through the medical model, it is easy to reduce them to their diagnosis (Kitwood, 1990). Some individuals believe that the characteristics of a person require the capacity to think, communicate and reason logically, therefore, excluding many individuals with dementia (Harrison, 1993).

The person-centred model acknowledges the individual, considering individuals' psychological, social, and emotional needs (Kitwood, 1997). Kitwood believed five fundamental psychological and social needs are required for an individual to maintain their personhood and experience a good sense of well-being- Identity, Comfort, Attachment, Inclusion and Occupation (Kitwood, 1997) (Figure 1.1). These five needs connect to the overarching need for love. Despite Individuals with dementia experiencing impairments in their abilities they still require all six needs. However, these needs can easily be forgotten during dementia care, especially in care homes.

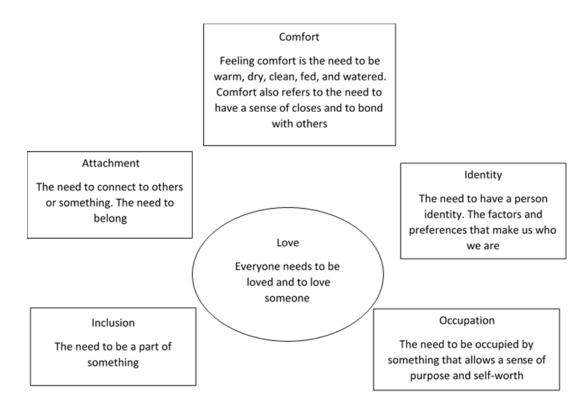


Figure 1.1 Kitwood's flower of emotional needs. The six fundamental psychological and social needs that all individuals require to maintain a good sense of wellbeing are Attachment, Inclusion, Comfort, Occupation, Identity and Love.

While person-centred care contributed significantly to changing the perception of dementia, there are some limitations, including the lack of concreteness of the approach, unclear theory components and how these can be implemented into practice, which is evident in the lack of consistency of the theory in practice (Witt & Fortune, 2019; Nolan et al., 2004). The ambiguity of the definition led to Brooker (2004) developing the VIPS framework to detangle the complex concept.

VIPS (Brooker, 2004, P216):

- Valuing people with dementia and those who care for them
- Treating people as individuals
- Looking at the world from the perspective of the person with dementia
- A positive social environment in which the person with dementia can experience relative well-being.

When considering person-centred care as more than individualised care as presented in the VIPS framework the discrimination of people with dementia can be reduced. Another limitation highlighted is that the theory improves the immediate interpersonal environment for the person with dementia, but it does not consider or engage with the wider socio-political context (Milne, 2020; Bartlett & O'Connor,2007). While the theory aims to individualise care and include the individual in decisions, some have argued that the approach does not recognise that the person with dementia has the capacity to exercise agency. The person-centred theory focuses solely on the individual's needs and individuality without considering the importance of the relationships with individuals who provide care (Nolan, 2004). While the individuals with dementia's personhood is at the forefront of the theory, the approach can lead to the carer's personhood being dismissed and neglected (Meranius et al., 2020). Previous research has highlighted that care homes can neglect to view care staff as an autonomous person, resulting in poor working conditions and their experience being reduced to a series of tasks, which in turn negatively affects the delivery of person-centred care (Kadri et al., 2018).

#### 1.2.2 Relationship-centred Care

The relationship-centred care approach aims to address the limitations of personcentred care by considering the needs of the individual in the context of others' needs (Wilson & Davis, 2009). The approach aims to capture the interdependencies and reciprocities of caring relationships to highlight the importance of formal and informal relationships in dementia care (Nolan, 2004).

Relationship-centred care is built upon four principles: 1) Relationships in health care need to include dimensions of personhood as well as roles, 2) Affect and emotions are important components of relationships in health care, 3) All health care relationships occur in the context of reciprocal influence, and 4) Relationship-centred care has a moral foundation (Beach et al., 2006). While some argue that Personcentred care focuses solely on the person with dementia's needs, views and wishes (Nolan, 2004), the relationship-centred care approach recognises both the person with dementia and those caring for them as individuals with a set of needs, wishes, values and experiences that could impact the care. The approach recognises the

importance of emotional support, suggesting that professionals should empathise with the person with dementia. Allowing emotions into the relationship can help the person with dementia experience their emotions, help the care professional understand the person's needs, and overall improve the care experienced (Beach et al., 2006). The approach aims to remove some of the power dynamics experienced in dementia care by acknowledging that the person caring for the individual can also benefit from the relationship, making both parties equal contributors to the relationship.

It has been argued that the approach conceptualises the person with dementia in a need-for-care concept as it only focuses on caring relationships developed with other individuals, disregarding relationships developed with the state or institutions (Kontos et al., 2017). In the relationship-centred care approach, the responsibility of care remains on the immediate formal and informal carers without highlighting or addressing the influence of wider social processes or profit-driven systems (Milne, 2020). Placing all the responsibility on the immediate carers can result in poor treatment solely attributed to the carer's fault without considering how policy and organisational priorities may have forced carers into providing poor treatment.

#### 1.2.3 The Social Model of Disability

While Person- and Relationship-centred care approaches focused on framing dementia in the construct of the individual with dementia and their immediate support system, the social model of disability frames dementia in the construct of the wider socio-political construct. Therefore, the problem of dementia is shifted from families and the individual to the wider society (Milne, 2020). The approach constructs dementia as a disability in which systematic and societal barriers impair individuals with a diagnosis. The approach suggests that people with dementia are disadvantaged as society is not developed to prevent their impairments from hindering their inclusion in society, including being unable to access services and public spaces, unable to access good quality care and contributing to family and community life (Shakespeare, 2017; Mental Health Foundation, 2015). The primary

aim of the social model is to create equality for those with disabilities, to empower individuals to make decisions about their care and life, and to enable them to live a full and fulfilling life. The social model of dementia aims to challenge societies' views of disabilities and dementia to eliminate the negative connotations and stigma, allowing individuals with dementia to be valued and included members of society and communities. The approach encourages care professionals to communicate meaningfully to ensure that the person is always central to interactions and decisions and is an active partner with feelings, values, a personality, and a life history (Ward, 2008).

While the approach removes the responsibilities from the individual and aims to place the individual central to interactions, individuals have argued that the model ignores the personal experience of dementia, instead reducing the complexity of the condition to environmental factors (Shakespeare, 2006). However, Oliver (2013) has argued that the model was created as a starting point to change the perspective of disability rather than aiming to be a comprehensive model. The social model of disability was initially developed to focus more on physical disability, in particular in younger populations. Therefore, it has been argued that the current social model does not fully capture the complexity and heterogeneity of dementia. While the social model may be beneficial in changing society's perception of disability despite its limitation, this does not mean that the model is suitable in terms of dementia as both society and many people diagnosed with dementia do not consider the condition as a disability instead it is usually framed as an illness or disease (Mental Health Foundation, 2015). Some have argued that using the term disabled may still cause stigmatisation as the term still has negative connotations.

## 1.3 Care Homes

Many cognitive, behavioural, and psychological symptoms significantly impact an individual's independence, ability to complete daily tasks and remain healthy and safe (Gallo et al., 2008). In the early stages of dementia, individuals may live relatively similar to pre-diagnosis with minimal assistance. However, the progression

of the condition leads to additional support, either formal or informal, being required to complete ADLs such as bathing, dressing, eating, and ensuring safety (Desai et al., 2004). Policies aim to extend the time people with dementia live independently in the community (Nolan et al., 2008). Family members and friends as informal caregivers are vital to ensure individuals can maintain some independence. Approximately two-thirds of individuals with dementia live in the community (Alzheimer's Disease International, 2009). The required time and caring commitments depend on the dementia symptoms and severity, but caring demands and responsibilities are generally challenging and increase with the condition's progression. When an individual's impairments no longer allow for sufficient and safe independent living, the decision may be made for them to enter long-term care. For some, this may be early in the condition when suitable support networks are not in place; for others, this may be when informal or formal caregivers are unable to fulfil caring demands in the community. Informal caregivers may be unable to continue supporting the individual due to inexperience in critical care, lack of available time, other commitments, or caregiver's health (Lindsay, 2008; Quince, 2013).

#### 1.3.1 Type of Care Homes

Long-term care facilities vary in their degrees of support, from sheltered living to nursing care homes. This thesis focuses on residential and nursing care homes and will refer to them as care homes. Approximately 69% of all individuals living in care homes have a dementia diagnosis (Prince et al., 2014). Residential and nursing care homes provide 24-hour care by trained care staff, with the degree of support varying depending on symptoms and severity. Nursing homes have the addition of a registered nurse because typically the residents living there have more complex medical conditions that require additional medical attention. Some care homes in the UK are registered as dementia-specialist; these homes aim to provide care by knowledgeable staff trained in dementia. Although individuals do not have to reside in the specialist dementia care home, non-specialist homes may lack the knowledge and experience to manage the challenges associated with dementia, leading to unmet needs (Alzheimer's Society, 2007).

The adult social care system, which includes care homes, functions in the shadow of the NHS with greater resources allocated to the NHS, which was exacerbated during the COVID-19 pandemic (Daly, 2020). Unlike the NHS, care homes are not free at entry; instead, there are fees for residents' placement. Care homes can be owned privately, by local authorities, or by charities, resulting in variations of practices and policies based on the owner's values, principles, and finances (Goyder et al., 2012). In 2013 90% of UK care homes were owned by a private organisation or owner (Quince, 2013). There is currently no maximum fee cap, with significant price variation (Learner, 2023). In 2022/23, residential care home places ranged from £686 a week in Northeast England to £955 in the Southeast. Similarly, the cost of nursing care home places ranged from £735 a week in Northern Ireland to £1,294 in the Southeast (Which? Money Team, 2023). Even within the same region, the cost of placements fluctuates considerably based on several factors, including the party responsible for covering the fees and whether the care home specialises in dementia.

Unlike the NHS, which has more consistency across services and trusts due to policies, there is more flexibility in the running of care homes. Providing care homes in England adheres to the safety standards outlined by the Care Quality Commission (CQC) and the Care Act, the management and operations of the care home are dictated by the respective organisations. In Wales, care homes are regulated by the Care and Social Services Inspectorate Wales, and in Scotland, The Care Inspectorate (Care inspectorate. Wales, 2021; Care Inspectorate, 2021). The Care Act requires local authorities to ensure that individuals are receiving services that are of high quality and appropriate to support their needs, gain appropriate advice, and have more control over their care. The act also outlines laws for the safeguarding of adults, the promotion of people's wellbeing, the promotion of integrated care and support within health services, assessing people's needs and information on how CQC is run (Department of Health, 2014). Other policies and procedures implemented in care homes will be influenced by the Care Act and the CQC regulations.

As mentioned previously, over 93% of care homes in the UK are privately owned, with the majority running for profit (74%) (Barron & West, 2017 & Health Investor UK, 2018). Therefore, decisions within can be influenced by their profitability. Residents' placements are either self-funded or funded by local authorities, the NHS, or other organisations, with the Local Authority's placements being means-tested. An individual is eligible for a partially funded local authority placement in England when their assets are below £ 23,250 and an entirely funded placement when their assets are below £14,250. Therefore, many care home residents are fully (37%) or partially self-funded (Frankova, 2018; Office for National Statistics, 2023). The thresholds vary in the other UK countries. The means test eligibility thresholds will be raised in 2025, impacting the number of individuals being fully self-funded (Department of Health and Social Care, 2022). Additionally, in 2025, the government will introduce a cap on the amount (£86,000) an individual spends on care homes throughout their life.

#### 1.3.2 The Marketisation of Care Homes

Before the 1980s, 80% of care homes were publicly owned (Barron & West, 2017); the move towards the marketisation of the social care system aimed to improve the cost efficacy and quality of care, giving individuals a greater choice (Brennan et al., 2012; Walker et al., 2022). Firstly, while the marketisation of care homes may have offered more choices to self-funded individuals who can afford to select their care home based on quality and provisions, for local authority-funded individuals, there is some choice, but the list of care homes offered are based on those that the funding would cover (NHS, 2022; Walker et al., 2022). These care homes usually have lower fees and, therefore, less funding for extra provisions such as music therapists and buses for trips. Secondly, research suggests that the marketisation did not improve cost efficacy and quality of care; instead, the opposite may be evident (Walker et al., 2022). For the local authority placements, the funds received by care homes do not fully cover the cost, with the Local Authorities paying £2.3 billion less than expected each year (The Guardian, 2023). The current funding system, plus the ownership of care homes, results in care homes being severely underfunded. With the continuing rising costs of living and care, underfunding will continue to be a challenge, especially as the ageing population grows (Walker et al., 2022). The Mental Health Foundation

suggested that budgets would need to rise by an average of 3.4% to meet the needs of future demands without considering improvements to the system. To improve the current system, at least an additional £3.1 billion by 2024/25 and £11.6 billion by 2032/33 would be needed (Boccarini, 2023). This is without considering how increasing the local authority eligibility threshold will impact funding. While there have been some attempts to improve the underfunding of adult social care, the system is still severely underfunded, and the impact of COVID-19 exacerbated the funding gap. The underfunding of care homes significantly impacts the care individuals receive.

As different organisations own care homes for either for-profit or non-profit, the variation in the quality of care provided is substantial (Bach-Mortensen, 2019). Previous research has reported that care homes with the highest profit margins are among those with the poorest quality of care and work conditions (Pollock & Harding-Edgar, 2020; Walker et al., 2022). Eighty-four per cent of local authority-run care homes score good or outstanding on their CQC inspections compared to 77% of for-profit homes (Pollock & Harding-Edgar, 2020). The marketisation of care homes has resulted in large financial equity firms owning several of the largest care home chains in the UK, which has led to predatory financial practices (Walker et al., 2022). For-profit care homes commonly have policies that restrict annual leave, decrease the staff-to-resident ratios, and prevent sick pay, leading to high levels of staff burnout, increased staff turnover, a risk to residents' safety, low quality of care, low levels of well-being for both staff and residents and create a negative public perception of the care sector (Burns et al., 2016).

### 1.3.3 Care Staff

Care home staff, particularly carers, play a vital role in the lives of residents due to residents relying heavily on them to complete personal care tasks such as dressing, washing, eating, accessing leisure activities and interactions. Being a carer can be physically, mentally, and emotionally demanding (Testad et al., 2010). In 2020/2021, approximately 1.54 million people worked in adult social care (Skills for Care, 2021).

Women hold 80% of adult social care positions, most working in direct care or support-providing roles. In the UK, the carer role can be viewed as a low-paid, low-status job, with many staff feeling undervalued by management, residents, families of residents, and the public (Carr, 2014; Lawrence et al., 2016; Skills for Care, 2020).

The current state of the UK care home system significantly impacts staff working in care homes (Burns et al., 2016). The marketisation of care homes has led to poorer working conditions, leading to high staff burnout and turnover rates. The recruitment and retention of care staff have been a long-standing issue, but the issue has worsened due to COVID-19 and Brexit (Randell, 2021). Care work is undervalued and underpaid, with poor working conditions. On average, the wage for a carer is 2% above the national living wage (£10.42) despite them having high levels of responsibility and the role being physically and mentally demanding (Health and Social Care Committee, 2020; Randell, 2021). Additionally, a quarter of care home staff are on zero-hour contracts (Foster, 2023); the lack of guaranteed regular hours results in income insecurity and unpredictable work schedules. The poor pay, unpredictable working hours, and lack of career path results in high turnover rates, with staff leaving the profession to find more stability where they are valued for their experience (Randell, 2021). In October 2021, on average, there was a 17% care staff vacancy rate (National Care Forum and Outstanding Managers Network, 2021). Not only does the lack of staff affect the care and safety of individuals residing in care homes, but there is also a significant impact on other staff and services, such as the NHS (Beech et al., 2019; Randell, 2021; Pitarella, 2020).

With the growing ageing population, the social care workforce needs to grow rather than shrink, which is currently being observed. While recruiting is challenging, it has been argued that there is a bigger challenge. It is not enough to fill the vacancies with workers; there is a need to fill vacancies with the right people with the correct values to ensure high-quality care (Pitarella, 2020). An emphasis on the lack of qualifications or previous experience needed has created false assumptions among the public that the job is easy and under-skilled, attracting people without the appropriate

knowledge, understanding or attributes for the role. Recruiting workers with a lack of knowledge, understanding, or attributes, such as empathy and compassion, can negatively impact the quality of care, with residents not receiving a sufficient level of attention, emotional support, and assistance (Pitarella, 2020). When individuals who are unsuited to the job are employed, there is an increased chance of only residents' physical health needs being met and an increased risk of abuse and neglect. Additionally, recruiting individuals unsuitable for the role can contribute to high staff turnover rates.

The recruitment and retention rates have always been challenging for care homes; however, leaving the European Union has exacerbated the challenge (Migration Advisory Committee, 2022). The UK care home workforce is diverse, with 7% of workers having EU nationality and 9% having non-EU nationality (Skills for Care, 2021). There was a drop in new workers migrating from other countries (1.8%) in 2021, potentially due to changes in immigration rules and COVID-19 travel restrictions. It was suggested that the limited migration due to Brexit could lead to a shortfall of 70,000 workers by 2025/26 due to people being unable to migrate to the UK to work as a carer due to the role being considered low-skilled (Dayan, 2017). However, in 2022 care workers policies were changed allowing non-British work as carers if they met the salary threshold and had a licenced sponsor which will help to manage the carers shortage (Skills for care, 2023).

Residents' dependency on care staff compels the need for a strong relationship based on trust, respect, and understanding (Graham & Bassett, 2006, Wilson & Davis, 2009). When this relationship is non-existent, residents can experience low quality of life and care and staff experience low job satisfaction and high burnout (Cook & Brown-Wilson, 2010; Jenkins & Allen, 1998; Willemse et al., 2015a, 2015b). The role's demands can lead to high staff turnover rates in care homes (Alzheimer's Society, 2007).

#### 1.3.4 Care Home Culture

Societal views on dementia and the treatment of diagnosed individuals have altered over recent years, decades, and centuries. Before the mid-20<sup>th</sup> century, individuals with dementia symptoms would typically be admitted to asylums or workhouses, neither suitable for these individuals (Andrews, 2017). They were seen as incurable and unmanageable, needing to be removed from society when family members could no longer cope. As dementia knowledge advances, the treatment of individuals with dementia has improved. A move towards care homes providing higher-quality care, including improving heating and reducing shared bedrooms, has occurred (Lievesley et al., 2011). The CQC standards advocate that individual be treated with respect, dignity, and individuality (National Health Service England, 2014). The culture in care homes significantly impacts the quality of care and life individuals with dementia experience.

A care home culture refers to the atmosphere, philosophy, and care priorities (Luff et al., 2011) and is critical for the provision of good care. When there is a strong care home culture, the staff as a collective share basic assumptions that are found to work as the team adapts to problems (Schein, 1990). When new members join the team, they are taught the assumptions as the right way to perceive, think, and feel. The strength and internal consistency of a culture relates to the stability and longevity of the group, the intensity of shared experiences, and the strength and clarity of assumptions held by management (Killett et al., 2016). The care home culture varies between care homes, and despite regulations to maintain high standards, some care home cultures negatively impact residents (Quince, 2013). A culture can manifest at three levels: 1) visible artefacts, 2) values, norms, and attitudes, and 3) assumptions (Schein, 1990). Visible artefacts include what people wear, how they speak to each other, the physical environments, documented policies, and stories told about the care home. Values include norms, ideologies, and philosophies that reveal the staff's thoughts and feelings about the care home. Assumptions are values held subconsciously.

As mentioned, previous care home culture began changing with the research into person-centred care and personhood (Kitwood, 1993), which articulated the need to move away from the view that physical health and safety are the sole priority. Instead, moving towards a culture that deinstitutionalises care homes, promotes the importance of psychological, social, and emotional needs, and recognises the individual behind the diagnosis (Zimmerman et al., 2014). Dementia has been referred to as a living death, especially in the media (Behuniak, 2011). However, views are changing to recognise that individuals with dementia are still people after their diagnosis who continue to have emotions, needs and worth in their lives (Lindsay, 2008). Care homes should provide support to enable individuals to continue living with worth and purpose. There is a need for a sense of community within a care home that includes residents, staff, and relatives. When this sense of connectedness is perceived by staff, the care home is seen first and foremost as the residents' home rather than their workplace, where staff are concerned not only about the residents but also relatives (Killett et al., 2016). These cultures that emphasise person-centred goals rather than organisational-oriented needs are more likely to provide residents with a positive care experience.

Although there is a consensus that person-centred care is required, in practice, there is less consistency between staff and care homes (Cooper et al., 2018), with many care homes still having a more task-orientated culture where the individual with dementia is seen as the 'patient'. In Cooper et al.'s study (2018), only one out of 92 care homes reported no cases of abuse or neglect. Although no physical mistreatment was reported, 5% reported verbal abuse, and many reported neglectful behaviours. Inflicting abuse and neglect holds significant consequences for staff; therefore, the reported numbers may be under-representative. Many care staff may be unaware of their neglectful behaviours, such as care homes offering limited leisure activities or opportunities to leave the care home, despite the need for activities being essential for individuals to maintain good well-being and personhood.

Starting in the 80s, the USA aimed to transform care homes through the culturechange movement. By incorporating person-centred care, the movement aimed to deinstitutionalise care homes, creating a more home-like atmosphere that individualises care and promotes the need for meaningful activities and interactions (Koren, 2010). The movement aimed to empower not only residents but also staff. In the early 2000s, little in-depth culture change had occurred; only 5% of interviewed care homes fully embraced the resident-centred culture. Forty-three per cent of care homes did not fit the resident-centred definition and had no plans to adopt the philosophy (Doty et al., 2008). The My Home Life Movement in the UK aligned with the USA culture-change movement (Killett et al., 2016). The movement promoted collaboration between the care industry, academics, and other stakeholders to influence the care home culture through leadership and management. The movement also aimed to change society's perception of care homes to alter perceptions away from the negative view portrayed by the media that residents in care homes are poorly treated towards a more positive view (Owen et al., 2012).

Management in care homes play a crucial direct role in their culture and, therefore, are vital in changing the care home culture (Killett et al., 2016; Owen et al., 2012; Orellana, 2014). Managers are responsible for everything that happens in the care homes and, therefore, are faced with a number of challenges daily, including contending with external negativity, lack of support from the health and social care community, staff difficulties, inadequate funding, excessive bureaucracy, and constant unpredictable changes that result from a fractured system (Killette et al., 2016; Orellana, 2014). They are the middle person between the care home owner, the staff, and residents and, therefore, must balance each stakeholder's priorities and needs to make sure that the decisions are profitable for the owners while ensuring high-quality care and conditions for their staff and residents. Management are usually the decision-makers of general day-to-day decisions, meaning it is essential that managers mediate external pressures so that they do not negatively impact the care delivered. The manager's attitudes, skills, and behaviours can influence the quality of care delivered, staff retention rates, inspection ratings, and

resident outcomes (Orellana, 2014, 2017). Despite managers having a significant influence on the care home culture and quality of care received, support for managers is insufficient. Effective management leadership is crucial when aiming to make changes to the care home culture or routines. When the manager is responsive and encouraging towards change, staff are more likely to implement and maintain change.

The care home culture is not only influential on resident care, but it also significantly influences the experience of the workforce, which subsequently influences the quality of care delivered. It is critical for staff to feel empowered, have autonomy, and take responsibility for residents' care (Killett et al., 2016). Having low preserved control and decisional authority alongside high levels of psychological demand, as seen in care workers, can lead to high levels of depression and anxiety (Stansfeld & Candy, 2006). Additionally, having a lack of autonomy over decisions can lead to low job satisfaction and, subsequently, higher staff turnover rates (Stagnitti, 2006). Care staff have reported valuing autonomy as it allows them to be flexible and regularly make changes to ensure that the care is suitable for their resident's needs (Jacobsen et al., 2018). It is argued that it is important for carers to be involved in decision-making as they work directly with the residents and, therefore, have built relationships and understanding with each resident.

Despite this, care staff's autonomy varies between countries and organisations within a country. In a five-country study, the care staff in the UK reported having little autonomy, with them being excluded from formal care processes, care planning, and decision-making (Jacobsen et al., 2018). The lack of autonomy was mainly observed in care homes belonging to large chains. In these care homes, all staff were excluded from decision-making, with decisions on daily routines such as the meal plan being decided by a central team who then distributed the same information to all the chain's care homes. Some participants reported feeling constantly watched, with there being a fear of being reported for doing something wrong; this can create conflicting struggles when incorrect behaviour is in relation to

the care home's standardised practices rather than it being harmful to the resident. Having a lack of autonomy over their daily routines threatens the concept of personcentred care, as they were unable to alter their behaviours to meet the individualised needs of their residents.

# 1.4 Communication and Dementia

As social beings, humans require regular interactions with others to ensure psychological, social, and emotional needs are met (Kitwood, 1998). Effective communication consists of verbal and non-verbal elements (Jootun & McGhee, 2011), with verbal communication only accounting for 7% of interactions. The other 93% consists of non-verbal elements including eye contact, smiling, facial expression, personal space, behaviours, and touch (Hegstrom, 1979; Okech et al., 2019).

For individuals with dementia, communication, in particular verbal language, can be challenging due to their impairments in cognitive function. However, communication is still required to participate in society and express wishes and preferences (Banovic et al., 2018). Individuals with dementia may lack the ability to remember correct wording, repeat themselves, or use confusing, nonsensical words (Veselinova, 2014), and the communication impairments can lead to individuals withdrawing from society and becoming socially isolated. As a result of their impairments, non-verbal communication may be more fundamental to interactions to ensure preferences, wishes, and emotions are expressed and understood (Okech et al., 2018). As dementia predominates in older adults, individuals may also experience impairments related to older age or other health conditions that can further impair an individual's communication ability (Stanyon et al., 2016). Impairments in vision and hearing may lead to missed communication, resulting in feelings of frustration and isolation (Parker, 2003; Veselinova, 2014).

# 1.4.1 Communication Within Care Homes

Communication is essential in nursing care as residents with dementia depend on carers to meet their physical, psychological, social, and emotional needs (Jootun &

McGhee, 2011; Willemse et al., 2015a, 2015b) to enable fully person-centred care (Kitwood, 1997). When effective communication is implemented and relationships developed, there are improvements in residents and staff's quality of life, staff burden, quality of care, job satisfaction, and reduced residents' disruptive behaviours (Eggenberger et al., 2013; Nguyen et al., 2019; Savundranayagram, 2014; Willemse et al., 2015a, 2015b). The COVID-19 pandemic highlighted how essential interactions are for residents. During the pandemic, social contact, activities, and residents' interactions with staff and visitors were reduced to mitigate the spread of the disease. This resulted in a large proportion of care home residents experiencing extensive deterioration in health (Alzheimer's Society, 2020; Gordon et al., 2020; Velayudhan et al., 2020).

Despite communication being a crucial care component, there is no mandatory requirement for specific accredited care staff training (Smith et al., 2019). Care homes may provide some training, but generally, this focuses more on residents' physical health and safety (Vella-Burrows, 2011). Several studies have explored effective communication training; however, it seems that research is not transferring to the practical setting (Smith et al., 2019). Staff-resident interactions have been documented as limited and insufficient (Ward et al., 2008). Language impairments and apathy can make initiating conversations challenging. Because of this, residents rely on other people to engage with them, especially care staff with whom they spend a large proportion of the day. However, reports indicate that residents spend much of their day not interacting with anyone. In one study, staff-resident interactions only occurred for 2.5% of the day (Ward et al., 2008) and only rose to 10% when including all interactions. These results are not isolated to one study; Willemse et al. (2015b) reported that their participants only experienced, on average, 1.5 meaningful interactions over a six-hour observation period, with onethird of participants having zero positive interactions. A lack of human contact can lead to many residents reporting high levels of loneliness. Care home residents are twice as likely (22-42%) to experience loneliness compared to similar communitydwelling individuals (Victor, 2012).

As mentioned previously, the role of a carer is demanding because residents with complex needs require time-consuming care and support (Testad et al., 2010). Demands on carers can lead to care homes prioritising residents' safety and physical care (Stanyon et al., 2016), leaving little time allocated to attend to residents' psychosocial needs, despite these being fundamental to residents' quality of care and life. Staff have also reported feeling pressure from management to complete tasks, with interactions not considered part of their role (Windle et al., 2020).

Additionally, staff interactions are generally short, and fragmented with little opportunity for residents to actively engage (Savundranayagam, 2014; Ward et al., 2008). Care home interactions, coined 'elderspeak', have been characterised by their simplistic vocabulary and grammar, shortened sentences, slow speech, elevated pitch, and inappropriate use of endearment (Caporael, 1981; Kemper, 1994; Williams et al., 2009). Elderspeak has been compared to communication used with babies, leading to residents feeling patronised. Elderspeak can negatively influence residents' quality of life, increase BPSDs, and resistance to care behaviours (Williams et al., 2009).

Not all staff and care homes have the negative communication style present above; many acknowledge the importance of meaningful interactions based on personcentred care (Stanyon et al., 2016). Meaningful interactions should be available to all individuals irrespective of their dementia severity and verbal language abilities and therefore, care staff should tailor them to the strength and impairments of each resident to ensure equal opportunities to connect with others (Savundranayagam, 2007). Whilst some believe some staff have innate qualities that lend to them providing meaningful person-centred communication, formal training is still required for many staff. In Savundranayagam's study (2014), despite staff having no formal training, over a third of recorded interactions used person-centred communication. Still person-centred communication the other two-thirds of recorded interactions.

Staff-resident interactions become increasingly challenging as the individual's dementia progresses and verbal language deteriorates (Paudel et al., 2019). A scoping review reported that care staff in four studies had reduced and poorer quality interactions with more physically dependent residents or those with more significant cognitive impairments (Van Manen et al., 2020). Reduction in verbal communication can result in reduced interactions, leading to individuals with dementia experiencing social isolation.

When verbal language deteriorates, residents can continue to communicate and interact meaningfully through alternative communication forms that remain accessible to individuals with dementia (Hubbard et al., 2002; Parker, 2003; Ward, 2008). Noises and behaviours generally considered as 'challenging behaviour' could potentially be individuals expressing themselves and their unmet needs when other forms of communication are unavailable (Stanyon et al., 2016; Ward, 2008). The use of non-verbal communication allows them to stay connected to the social world and maintain their personhood (Cook & Clarke., 2010). One study set in a day-care centre discovered that participants had altered their non-verbal behaviours to become meaningful and their primary forms of communication (Hubbard et al., 2002). The use of touch could signal their wish to engage in interactions, provide proximity to the speaking individual when hearing was impaired, or even provide reassurance. Certain behaviours, such as holding their walking stick, allowed individuals to convey to staff messages that the person found embarrassing such as needing the bathroom. However, it is important to recognise that the subtly and ambiguity of non-verbal communication may lead to it being missed or misinterpreted.

### 1.5 Psychosocial Interventions

Although most dementia conditions are incurable, pharmacological, and psychosocial treatments can improve neuropsychiatric and cognitive symptoms and quality of life (Alzheimer's Association, 2020b). Research indicates that the benefits of pharmacological treatments are limited and can cause adverse side effects (Ballard et al., 2009; Gauthier et al., 2010). Therefore, psychosocial interventions may be the

preferred form of treatment due to their effectiveness and limited side effects (Gauthier et al., 2010; Howard et al., 2001). Psychosocial interventions aim to manage dementia symptoms, in particular BPSDs, promote independence and maintain function (National Institute for Heath and Care Excellence (NICE), 2018). Psychosocial interventions encompass various treatments, including Tailored Activities Programs, Exercise, Art Therapy, Aromatherapy, Cognitive Stimulation Therapy (CST), Reminiscence Therapy, and Validation Therapy (Berg-Weger & Stewart, 2017; Oliveira et al., 2015). Interventions can be completed individually or as a group and provided by carers, family members, or specialist professionals in the community or care homes (National Collaborating Centre for Mental Health, 2007). The appropriateness of interventions depends on dementia type, severity, personal preferences, and the targeted symptoms. However, most interventions are adaptable to the individual's needs and abilities, making them more likely to be effective.

Most treatments target the individual with dementia; however, the condition significantly impacts caregivers, whether formal or informal. Therefore, some interventions aim to train and support the carer (Elvish et al., 2012; Pusey & Richards, 2001; Yasuda & Sakakibara, 2017). Although aimed at the carers, the skills and knowledge learnt can, in turn, improve the individual with dementia's BPSDs, the quality of life for both the individual with dementia and the carer and reduce carers' stress. Music is one evidence-based psychosocial intervention regularly used in dementia care.

# 1.6 Music and Dementia

Music has existed for centuries, integrated into everyday life as a source of enjoyment and relaxation, it appears to be central and fundamental to all cultures (Park, 2020), and used as a psychosocial intervention for many conditions including dementia (McDermott, 2014; McDermott et al., 2018, 2019).

#### 1.6.1 Music Processing

Music processing is apparent in early development, with babies responding to the pitch and rhythm of their mother's voice (Zatorre, 2005). Some individuals argue that the ability may even be innate. Humans continue to process music throughout their life, with research implying that music processing continues to persist during the stage of dementia when other brain functions dimmish (Baird & Samson, 2015; Devere, 2017). Even in the late stage of dementia individuals have been observed engaging with music through listening, singing, and playing instruments (Brotons & Koger, 2000). Unlike language, processed mainly in the left hemisphere, music processing requires nearly every brain area, which could explain why it remains intact when language abilities are severely impaired (Levitin, 2008; Peretz & Coltheart, 2003). Music processing remains intact during dementia, making it a potential alternative to traditional verbal communication to facilitate social interactions in individuals with language impairments (Chatterton et al., 2010). Music allows individuals with dementia to self-express, maintain an identity and connect with others (Hsu et al., 2015; McDermott et al., 2014b).

#### 1.6.2 Music Interventions

In todays' society, music as a treatment has been questioned due to the difficulty of obtaining objective evidence and its subjectivity (Park, 2020). However, the use of music therapeutically has been well established in history across cultures and times (Sonke, 2011). Music was a vital element in indigenous culture's healing rituals allowing individuals to enter the spiritual realm (Sonke, 2011). Although the beliefs and rituals of the indigenous cultures are very different to music in healthcare today, many of the foundations are the same. Both practices are rooted in connecting and communicating with our emotional side. Over centuries, therapeutic music has evoked to resemble our concept in western societies today. Although used for many years, it has not been easy for music interventions to be accepted (Park, 2020). The Flexner report (1910) negatively impacted the acceptance of music intervention after doubting its effectiveness due to a lack of significant scientific evidence and qualitative methods, leading to medical teachings excluding psychosocial aspects of illness (Park, 2020). As mentioned previously, in dementia, individuals' psychosocial

needs are equally essential as their physical needs, and treatments should be personcentred where the whole individual is considered (Kitwood, 1997). In recent years, therapeutic music has increased in popularity resulting from further evidence-based studies being conducted, with individuals recognising the benefits of music as a psychosocial intervention, especially in dementia care (Park,2020, McDermott et al., 2019).

Music interventions are generally categorised into two types, Music therapy facilitated by specialist music therapist (Schneider, 2018) and music activities facilitated by anyone regardless of musical experience. The most appropriate music intervention to implement depends on the individual, dementia symptoms, and aims for treatment.

#### 1.6.2.1 Music therapy

In recent decades, music therapy has gained popularity as an alternative therapy to improve symptoms and well-being in various populations and conditions, including dementia (Hara, 2011; McDermott et al., 2018). The therapy aims to work with individuals to achieve therapeutic goals and develop therapeutic relationships through music and musical elements to meet individuals' psychological, social, and emotional needs (British Association for Music Therapy, 2017; Schneider, 2018). A trained music therapist who, in many countries, requires a postgraduate qualification and is registered with a regulating body delivers the sessions. In the UK, music therapists are registered with the Health and Care Professions Council (HCPC) (Schneider, 2018), with approximately 200-250 music therapists registered working in the dementia field who mainly work within care homes. Sessions can be provided individually or in small groups, using music activities including singing, musical instruments, movement, music and relaxation exercises, lyrics discussions and song writing. Therapists use a range of skills, including validation, reminiscence, arousal regulation, empathy, holding, containing, turn-taking, and modelling (Hsu et al., 2015; Kydd, 2001; Lesta & Petocz, 2006; Ridder, 2003; Ridder & Aldridge, 2005; Ridder & Gummesen, 2015).

Research highlights a variety of significant benefits for music therapy in dementia care, including social participation, mental stimulation, improvements in memory, agitation, alertness, and depression (Aldridge, 2000; Bannan & Montgomery-Smith, 2008; Ray & Götell, 2018; Ridder et al., 2013; Svansdottir & Snaedal, 2006). Although music therapy can effectively improve dementia symptoms and quality of life, the intervention is available to a limited number of individuals, partly owing to the limited number of dementia-specific music therapists (Schneider, 2018). Additionally, although music therapy can be more cost-effective than other treatments, many care homes have limited available finances and resources to employ a music therapist.

### 1.6.2.2 Music Activities

Music activities provided by care staff, volunteers, or musicians, can be an alternative to music therapy. Research suggests that music activities can be equally effective as music therapy and sometimes may be more suitable due to their flexibility and the ability to provide them regularly (Dahms et al., 2021; Raglio et al., 2012). If structured and implemented effectively, they can have similar therapeutic benefits to music therapy, including improved memory recall, language skills, aggression, agitation, social behaviours, isolation, and relationships (Götell et al., 2002; Raglio et al., 2012; Sixsmith and Gibson, 2007; Van der Vleuten et al., 2012; Wall & Duffy, 2010). When facilitated by care staff, staff can experience improved quality of life, job satisfaction, communication skills, and reduced stress and burden (Swall et al., 2020). Music can aid staff in recognising the person behind the diagnosis, facilitating the development of more meaningful relationships (Campbell et al., 2017; Clare et al., 2019; Hsu et al., 2015).

Music activities can take different forms; they can be active, where the individual directly engages, including singing, dancing, or playing musical instruments (Sixsmith & Gibson,2007), or can be passive, where the music occurs without direct engagement, including listening to live or recorded music. Research suggests that active music may be more beneficial for individuals with dementia (Raglio et al., 2015); however, passive music listening is beneficial in some situations, including

during night-time or when agitated. Music activities can be an isolated or shared experience, and both can be beneficial to target different outcomes. However, generally, music in care homes consists of live performances or recorded music.

#### 1.6.3 Music Intervention in Care Homes

Using music while completing other tasks, such as personal care and mealtimes, has been highlighted as beneficial for individuals with dementia by improving the time efficiency and task effectiveness (Götell et al., 2002, 2003, 2012; Hammar et al. 2010, 2011a). Including music in care tasks can improve the caring experience for both residents and staff, as highlighted in a series of articles exploring Music Therapeutic Care (MTC) (Engström et al. 2011a, 2011b; Götell et al., 2002,2003,2009, 2012; Hammar et al., 2010, 2011a,2011b, 2011c). MTC involves carers singing during personal morning care, mealtimes, and personal transfers compared to usual care. Improvements in behaviour, language, mood, and impairments were observed when staff introduced singing.

The ease of implementation, low costs, and the ability to be facilitated by staff can make music activities more suitable for some care homes (Herbert et al., 2018; Thomas et al., 2017). However, it seems that research is not transitioning successfully into practice. In 2017, only 5% of care homes provided good quality arts and music interventions (Bamford & Bowell, 2017). This statistic explored all art provisions; therefore, the number of care homes providing music-specific interventions could be lower. The quality of music activities may vary between care homes depending on the ownership, management, staff employed and available funds. McDermott et al. (2018) suggested that the benefits of music may only be apparent when high-quality interventions are successfully implemented. Otherwise, they may be ineffective and even harmful to residents.

Allison & Smith (2020) explored one care home that displayed a fully immersed musical resident experience. The care home employed 28 activity staff providing daily art and music activities from 9am - 7:30pm. Residents also had access to an art

studio and musical instruments to use at their leisure. Participants felt that incorporating music into the home built a sense of community where all individuals were included despite their impairments. The use of music allowed residents to feel equal to staff by participating in public events such as concerts. The activities provided residents with a sense of autonomy and normalised identity. The identity of being a patient was removed, with some gaining new identities as musicians, painters, and songwriters. Overall, music and the arts aided the development of reciprocity, improving residents' quality of life. The care home described above displays an integrated music program; however, this is unrealistic for many care homes.

#### 1.6.4 Factors Influencing Implementation of Music in Care Homes

Many care homes hold positive views of using music in care, but many barriers prevent successful long-term implementation of music interventions. In Sung et al.'s (2011) study, despite holding positive views on music in dementia care, only 30.8% of staff used music with residents, with them suggesting numerous potential barriers preventing implementation. The primary barriers presented by staff were limited resources, knowledge, and time. Similar to engaging in meaningful interactions, there is limited available staff time to provide active music activities; (Batt-Rawden & Storlien, 2019; Garrido et al., 2019; Sung et al. 2011). However, The MTC studies highlighted the plausibility of incorporating some form of effective music intervention into daily routines when staff's time is restrictive (Engström, 2011a, 2011b; Götell, 2002, 2009; Hammar, 2010, 2011a, 2011b, 2011c). MTC allows staff to provide music while completing essential physical care. Therefore, the barrier may be a lack of available training and resources teaching successful implementation of music interventions into time-constrained routines.

Although music can be incorporated into other tasks, the staff in Batt-Rawden & Storlien's (2019) study reported that initially exploring residents' music preferences was time-consuming, especially when residents had limited verbal communication, leading to staff needing to use alternative forms to discover preferences. Whilst

exploring residents' music preferences may be time-consuming, this can provide a vital time for staff to discover the individual behind the diagnosis through conversations and reminiscence. Once residents' music preferences have been documented, using music during daily care could make task completion efficient and save care staff time (Engström, 2011a, 2011b; Götell, 2002, 209; Hammar, 2010, 2011a, 2011b, 2011c). Ekra & Dale (2020) also reported that resident improvements could lead to the intervention being time and resource-saving.

Care homes consist of a variety of job roles, and psychosocial interventions generally require collective teamwork to implement them successfully and effectively. Many studies discovered resistance to implementation from management and staff (Batt-Rawden & Storlien, 2019; Garrido et al., 2019). When management is enthusiastic about interventions, they can encourage staff to use them, whereas when management is unsupportive, they may not provide staff with the required time, resources, or support to use the intervention and may prioritise other tasks that align with their care home priorities. The participants in Ekra & Dale's study (2020) were enthusiastic about the intervention at the study start and recognised the benefits. However, staff enthusiasm and motivation lapsed once the formal training ended, and the music therapist was not providing regular in-house support. With the drop in music usage, the positive impact on residents also decreased.

Garrido et al. (2019) suggested that the primary barrier to implementing music interventions was cost related. Many facilities could not afford regular music therapists or music performers. Even obtaining resources such as iPods for personalised music listening was financially unavailable for some care homes.

# 1.6.5 Person-centred Music Care

Many care homes play music in communal areas to create a pleasant experience; however, generally, the music is not tailored to the residents (Van der Geer et al., 2009). From personal clinical experience, genres generally consist of war songs or contemporary pop radio stations. Although war songs may evoke reminiscence in

some residents; for other they may elicit negative memories, leading to distress. Additionally, as years pass, more residents are of an age where they cannot relate to the war or the music from the time. Similarly, care staff may listen to contemporary pop music as this is their preferred music genre, but residents may be unable to relate and, therefore, not engage with it (Paolantonio et al., 2021). Music taste is personal, developed over time and influenced by life stories. In one study, residents perceived modern music as different from the past and therefore it was not appreciated as they found it difficult to understand and it did not convey emotions leading to residents not connecting with the music (Paolantonio et al., 2021). Interventions may be ineffective if residents cannot connect with the chosen music.

Music interventions should be person-centred, tailored to the individual's preferences, wishes, and needs (Bowell & Bramford, 2018). Residents should be actively involved in designing their music intervention when possible. Despite many music interventions aiming to meet individuals' psychological, social, and emotional needs, many do not individualise or consider residents' music preferences (Hackett et al., 2021). Instead, one intervention design is applied to all individuals despite the heterogeneity in abilities and goals. For many studies, the main goal is to reduce neuropsychiatric symptoms. However, different symptoms benefit from different interventions. Hackett et al. (2021) also argue that many individuals with dementia are reduced to their symptoms, despite many behaviours being justified for the situation they are experiencing. For example, experiencing anxiety and depression due to transitioning to a care home which is confusing and isolated, is an appropriate reaction. Hackett et al. (2021) argue that considering behaviours in relation to the individual's circumstances can alter the implementation of music interventions. For example, instead of using music to manage 'problem behaviours', music can offer comfort and promote personhood, improving residents' quality of life. Hackett et al. (2021) proposed that instead of aiming research and music interventions to relieve symptoms, we should move towards more person-centred goals such as Kitwood's six fundamental needs.

#### 1.6.6 Adverse Effects of Music

Extensive research highlights the positives of music for individuals with dementia. However, the potential adverse effects of music for these individuals should not be dismissed. Whilst music can be a powerful tool to aid reminiscence, not all residents might like music, and may also equally invoke negative memories resulting in distress (Garrido et al., 2019; Silverman et al., 2020). Whilst care staff are often aware of this, it has been reported that such awareness is not ubiquitous (Garrido et al., 2019). Adverse evocations can be mitigated by exploring a resident's music preference and by providing awareness of this pitfall to care staff (Garrido et al., 2019; Krøier et al., 2020).

### 1.6.7 Music Skill-Sharing

In recent years, music therapists have seen increased opportunities to collaborate with care staff, family members, and community musicians to share their skills and knowledge (McDermott et al., 2018). Skill-sharing allows for an increase in indirect music therapy practices to be introduced into dementia care when music therapists are unavailable to provide clinical practises. It is becoming common for therapists to share therapeutic skills, which can be incorporated into staff's daily routine to allow benefits to continue outside of therapy sessions. As mentioned previously, music interventions must be high quality and well-informed to ensure efficacy and safety (McDermott et al., 2018). The delivery of music interventions is equally vital as the specific content. As highlighted in previous research, many care staff and family members may lack knowledge and experience in dementia and music interventions (Garrido et al., 2019, 2020; Robinson et al., 2014; Sung, 2011; Werner, 2001). Inappropriate or lack of space and support, that allows staff to reflect on how to be with the individual can lead to a loss in benefits (McDermott et al., 2018). Skillsharing allows therapists to withdraw when formal therapy ends, with the residents still being supported through music.

As mentioned previously, the availability of music therapists is limited, especially in the UK; therefore, music therapy and skill-sharing are limited to a small number of

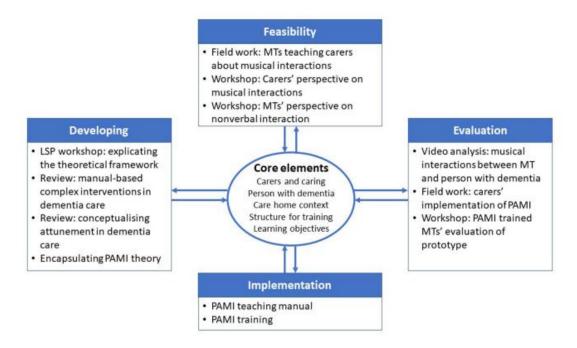
care homes (Schneider, 2018). Additionally, the training care staff receive is from music therapists' experience; therefore, there is reduced consistency between therapists. Manual-based interventions exploring the integration of music therapy skills into care home routines through staff training are currently limited (McDermott et al., 2018). Therefore, there is a need for a structured manual developed from evidence-based practices to train staff in music. The manual should focus on the type of music activities and the delivery by the facilitator to connect with residents. A skills-sharing manual would allow music therapists' knowledge to be shared and accessible to a larger population of care homes.

# 1.7 Person Attuned Musical Interaction (PAMI)

Person Attuned Musical Interaction (PAMI) is an evidence-based staff training intervention aiming to provide care staff with music therapy skill-sharing training. The tool consists of a manual and training package to provide care staff with knowledge and guidance on musical therapeutic skills that can be incorporated into care homes (Ridder et al., 2022, 2023). The manual aims to promote and facilitate more meaningful two-way attuned interactions between care staff and residents with dementia. A team of music therapist researchers at Aalborg University, Denmark, developed PAMI-DK (Ridder et al., 2022,2023). The original team trained music therapists in the principal and practises of PAMI for them to attend care homes to train care staff. The manual consists of indirect music therapy practical skills and techniques used by music therapists to develop relationships to improve symptoms and quality of life. The training aims to make care staff more aware of how they interact with residents and to reflect on their practices. The skills learnt by staff allow residents with dementia to become equal communication partners by highlighting the importance of non-verbal communication skills. The tool highlights residents' strengths without limiting them due to their impairments.

The team that created the PAMI-DK used the Medical Research Council (MRC) Guidelines for complex interventions during the development process, with them conducting several studies for each step (Figure 1.2). The Development of PAMI-DK

consisted of 12 sub-projects beginning with the development stage where they explored the concept of attunement, care home interactions and PAMI through systematic reviews and Lego serious play (LSP) which resulted in the development of the PAMI-DK resources and PAMI theory book. The next stages were to explore elements of PAMI to test the feasibility and acceptability which was achieved through three sub-projects with music therapist and carers. The evaluation stage consisted of evaluating music interactions, staff's understanding of music interactions using a PAMI protocol and music therapists' evaluation of the PAMI resources. The other three stages led to a final PAMI manual being developed and beginning to be implemented into Danish care homes.



*Figure 1.2 Figure from the PAMI-DK intervention development process as presented in Ridder et al. (2023)* 

### 1.8 Attunement

PAMI main aim to promote two-way attuned musical interactions between staff and residents with dementia. "Attunement refers to a mutual phenomenon that occurs between two or more people, with their emotional states influencing the dynamic process between them" (Krøier et al. 2020). There is little dementia research documenting attunement in care relationships. Although previous research has

highlighted the concept without explicitly referring to attunement. A systematic review by Alsawy et al. (2017) explored different communication strategies used in care homes, with one consisting of interpersonal characteristics focusing on 'attunement' and personhood. Care staff reported "being" in communication by attuning to the resident's feelings and perspectives rather than "doing" communication. Using the term attunement in dementia research may be less documented; however, the concept is longstanding in developmental psychology with it being a core component of infant and carer interactions (Papousek, 1979). Stern (1985), a key researcher in attunement, explored the connection between infant and caregiver, mainly consisting of non-verbal processes.

Many person-centred core components are also vital for attunement. To attune, the individual must take the perspective of the other, having a genuine interest in the person behind the diagnosis (Krøier et al., 2020). The caregivers must be aware and attuned to the individual's needs, wish and beliefs, attuning to their personhood (Palmer, 2014). In dementia care, attunement requires care staff to involve themselves emotionally in the interaction to acknowledge the resident's emotions and needs. Participants in the MTC study (Hammar et al., 2010) reported feelings of loneliness and powerlessness due to one-sided interactions. Attuned interactions create a feeling of reciprocity that relieves loneliness for residents and creates staff satisfaction (Krøier et al., 2020; Hammar et al., 2010), allowing the resident and care staff to live in a moment of equality. The systematic review by Krøier et al. (2020) reported that residents' psychosocial needs are met when reciprocity is achieved, and communication can occur easier and smoother.

### 1.8.1 Attunement in Music Therapy

In music therapy, therapists are trained to musically attune to patients to aid the development of therapeutic relationships. However, the training of this deeper connection is lacking in care staff training (Krøier et al., 2020). The use of music to achieve attunement may be more arbitrary to care staff. Even when not using music

directly, interactions contain musical elements vital for attunement (Krøier et al., 2020).

The core component of attunement is connecting to the other individual's perspectives. Therefore, the ability to alter communication style to match is essential. Adjusting the tempo ensures that both parties interact equally without the carer controlling the interaction (Jost et al., 2010). Research has previously highlighted that care staff and residents can interact at different speeds, with the staff member sometimes working faster than the resident can process (Hammar et al. 2010, 2011a, 2011b). Turn-taking is a crucial skill in music therapy to ensure that the interaction actively involves the resident, allowing them to stand as an equal individual (Clare et al., 2019; Jost et al., 2010; Ridder & Gummesen, 2015). The voice can be altered and adapted to attune to the individual with dementia; for example, the tone can convey different emotions (Krøier et al., 2020). Interactions can occur successfully when the tone matches the other individual's needs. A misalignment in the carer's voice and the resident's needs could negatively impact the individual and situation.

Although staff may lack attunement vocabulary (Häggström, 1998), the ability to recognise musical elements in interactions is believed to be innate (Krøier et al., 2020). Communicative musicality explores the innate capacity to use musical paraments, including timing, tempo, and dynamic patterns of sounds in interactions (Malloch, 1999). Babies and mothers have been observed communicating despite the baby being unable to understand the context of the mother's words and responding with nonsensical sounds. When observing babies' and mothers' interactions, they generally consist of wordless songs, rhythmic reparative nonsensical sounds, and imitation, all which babies seem to recognise and respond to. Babies can discriminate timing, pitch, volume, harmonical intervals and voice quality from an early age. Communicative musicality seems to remain intact in individuals with dementia. Therefore, the techniques can be adapted for dementia care to allow individuals to use musical elements to attune (Krøier et al., 2020; Ward et al., 2008).

### 1.9 Gap in the Literature

Music therapy skill-sharing is relatively new; therefore, there is currently a lack of clarity on which music therapy and non-verbal skills are transferable. Additionally, there is limited evidence on the applicability of musical interaction in care staff practices (Kroier, 2022; McDermott et al., 2018). PAMI was developed as a conceptual framework to describe the nonverbal musical interactions that happen spontaneously between caregivers and persons with dementia. The work by Ridder's team (Krøier, 2022; Ridder et al., 2023; Anderson- Ingstrup, 2020) aimed to support the application of PAMI in dementia care and to support music therapists in delivering music therapy skill-sharing. The program allows care staff to reflect on their practices, explore musical interactions, and create a shared professional language to verbalise their experiences and practices (Krøier, 2022).

As the results from the Danish studies (Ridder et al., 2023; Krøier, 2022) were presenting promising results, it was decided to introduce a version of PAMI to the UK. However, the efficacy of a psychosocial intervention in one country does not guarantee efficiency in a country different from the country of origin (Hutson et al., 2014); therefore, when planning to introduce PAMI to the UK, cultural adaptations were required to improve the likelihood of efficacy and implementation. Additionally, the original PAMI delivery trains music therapists to deliver the training to care staff. As highlighted earlier in the chapter, music therapy is limited to a few UK care homes with the finances and who prioritise funds for psychosocial interventions. Adapting the PAMI training to be delivered to care staff directly by the PAMI-UK team could make the training more accessible to a wider care home population, including those with limited finances. PAMI-UK aims to be a compacted version that can be delivered quickly to care staff. Finally, the researchers at Aalborg University are all involved in training less-experienced music therapist; therefore, they could use their networks to train Danish music therapists. Whereas the UK researchers are not affiliated with any UK Music therapy training courses. Due to the lack of a network, having a PAMI-UK team consisting of two music therapists who directly trained care staff was more practical to enable the team to offer training quickly to care staff.

# 1.10 Aims

- Conduct a systematic narrative synthesis review to explore how care home music interventions facilitate social interactions between care staff and residents with dementia.
- 2. Develop a UK training resource based on PAMI-DK that is culturally appropriate for UK care homes.
- Conduct a manual field-testing study to pilot the training format and evaluate its content validity, including cultural appropriateness, suitability usability, readability, and clinical relevance.
- Conduct a manual evaluation study to investigate its implementation process in a care home setting and collect preliminary data to determine the effects of PAMI-UK on residents with dementia and care staff.

2. Analysing the Use of Music to Facilitate Social Interactions in Care Home Residents with Dementia: Narrative Synthesis Systematic Review

This chapter has been adapted into an article: Waters et al (2022). Analysing the use of music to facilitate social interactions in care home residents with dementia: Narrative synthesis systematic review. Dementia (London), 21 (6), 2072-2094. https://doi.org/10.1177/14713012221100625

### 2.1 Introduction

Transitioning into a care home can be stressful and upsetting, as many feel they are losing their home, identity, and independence (Thein et al., 2011). The transition can be especially frightening for individuals with dementia, whose impairments such as memory loss may make the care home seem scary, confining, and isolated (Wiersma & Pedlar, 2008). Relationships developed between carers and residents impacts residents' well-being and quality of care (Willemse et al., 2015a, 2015b). Despite this, residents can experience a lack of stimulating interactions or activities (Schreiner et al., 2005), potentially due to carers' demands and high workload pressures or residents' language impairments (Moyle et al., 2013). As dementia progresses, individuals may retreat from social interactions when impairments initially develop due to embarrassment and frustration (Banovic et al., 2018; Veselinova, 2014).

Music can support communication, even when language deteriorates (Cross, 2014). The ability to continue to process music through the dementia stages allows individuals to continue to engage with music, making it a potentially helpful tool for residents to interact with others and express themselves (Brotons &Koger, 2000; Jacobsen et al., 2015; Peretz & Coltheart, 2003).

While many systematic reviews have explored the effects of music, many focus exclusively on music therapy, or not solely on social interaction outcomes (Brotons et al., 1997; Fusar-Poli et al., 2018; McDermott et al., 2013; Petrovsky et al., 2015; Van der Steen et al., 2018; Vink & Hanser, 2018). To our knowledge, this is the first

systematic review to explore how care home music interventions may facilitate social interactions, including both quantitative and qualitative studies. The data collected, identified previously researched interventions and their efficacy, which can aid the development of future music interventions to improve care home interactions. This review investigates the quality, efficacy, and care home music intervention mechanisms to facilitate social interactions. This review will also explore whether the mechanisms for social interactions differ for music therapy compared to music activities.

# 2.2 Methods

This review was conducted using a prespecified protocol and in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statement (Moher et al., 2009). A narrative synthesis was conducted due to the flexibility of the approach, allowing for the exploration of the mechanisms for how and why care home music interventions facilitate social interactions, in studies with considerable heterogeneity in methodology, interventions, and participants (Popay et al., 2006). Popay et al.'s (2006) four-element framework was used to answer the following research question: How do care home music interventions facilitate social interactions for residents with dementia?

# Popay's (2006) four-element framework

1) Developing a theory of how the intervention works, why, and for whom (Presented in Methods)

2) Developing a preliminary synthesis of findings of included studies (Presented in Findings)

3) Exploring relationships in the data (Presented in Findings and Discussion)

4) Assessing the robustness of the synthesis (Presented in Findings and Discussion)

# 2.2.1 Narrative Synthesis Element One: Developing a Theory

Music in dementia care has several roles, including music as a leisure activity to contribute to well-being (Laukka, 2007), cognitive decline prevention (Klimova et al., 2017) and altering BPSDs in people with dementia (Ellewela et al., 2021). The roles and aims of music therapy and music activities differ. Music therapy is a controlled use of music (Munro & Mount, 1978), with the elements and skills used being an intentional decision from the music therapist to achieve therapeutic goals and develop therapeutic relationships to address an individual's psychological, social, and emotional needs (British Association for Music Therapy, 2017; American Music Therapy Association, 2023; Schneider, 2018). Music therapy is a clinical and evidence-based use of music interventions (American Music Therapy Association, 2023).

Whereas music activities are generally used for health promotion or recreational goals (Stegemann et al., 2019). Music activities in care homes are generally less intentional. Having music on in care homes has become a natural practice that staff continue as it has become the normal. Generally, there is less reflection on the type of music played; instead, staff play songs that either they like, the residents like or what they think residents should like. While there are some evidence-based music activities, overall, music in care homes is everyday passive music listening that is an integral part of human life without the staff considering the therapeutic benefits above residents' enjoyment. Music activities generally have broader aims and lack a specific intervention model, long-term goals, and a specific therapeutic setting (Spiro, 2010). Raglio and Gianelli (2009) argue that the main difference between music therapy and music activities is the absence of long-term goals in music activities. Although the aims differ, previous research highlights that benefits can be similar if implemented successfully.

Several theoretical frameworks have been proposed to explain the concepts behind music therapy as a treatment. A conceptual model of music therapy has been proposed that includes using antecedents (vibration, sound, tone, timbre, intensity, and tempo) and attributes (rhythm, melody, pitch, harmony, interval) to influence consequences (Psychological and physiological responses) (Murrock & Bekhet, 2016). Music consists of five elements that are closely related, interdependent, and nonhierarchical: rhythm, melody, pitch, harmony, and interval (Bunt, 1994). In Music therapy, these five elements are recognised and manipulated. For example, the music therapist may consider the rhythm of the music used when wanting to capture the person's attention. Whereas the melody would be considered when using music as a communication tool. This in-depth reflective depiction of music would not be seen in most music activities delivered by care staff.

The heuristic working factor model for music therapy aimed to draw on previously proposed frameworks to create a more inclusive complex model (Hillecke et al. 2005). The model draws on five factors: attention modulation, emotion modulation,

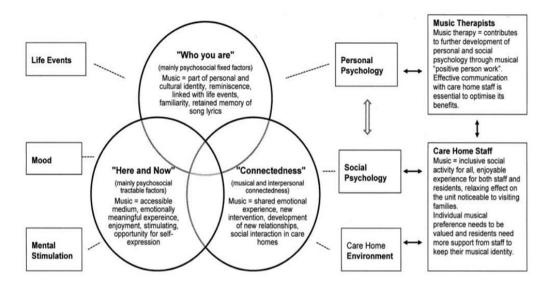
cognition modulation, behaviour modulation and communication modulation. The theory suggests that music can be used to attract attention, facilitate movement and behaviour, facilitates communication, and regulate emotions.

Several frameworks also exist to explain the concept of music interventions in general without distinguishing between music therapy and music activities. One framework is the Progressively Lowered Stress Threshold Model (Hall & Buckwalter, 1987; Petrovsky, 2014), which suggests that music can decrease stress levels from 'anxious' or 'dysfunctional' to the individual's 'functional' level. Individualised Music Intervention for Agitation is a framework that stemmed from Hall & Buckwalter's' work (1987). The framework aims to understand how music reduces stress in individuals with dementia who are experiencing agitation by exploring the use of music to create pleasant memories to soothe while also using music to stimulate and orientate (Gerdner, 1997).

The Theoretical Framework of Music Therapy in older adults with dementia uses the work of the Heuristic Working Factor Model for Music Therapy but does not distinguish between music intervention type but instead, focuses on the attributes of the music experience, which is then explored in relation to the five domains of dementia-related health changes (Physiological, psychosocial, physical, cognitive, and spiritual) (Petrovsky, 2014). The framework suggests that music affects humans' attention, emotions, cognition, motoric behaviour, and socialisation, with the outcomes affecting all aspects of the individuals.

Despite extensive research into music therapy and music activity, there is a lack of consensus on the concepts behind the interventions and whether these are similar or different between music therapy and music activities (Petrovsky, 2014). While there is some research on the concepts behind music therapy and music activities, more evidence is needed; there is still little understanding in the field of the mechanisms of the two intervention types for people with dementia.

When exploring how music facilitates communications McDermott's et al's. (2014b) Psychosocial Model of Music in Dementia (Figure 2.1) highlights several potential mechanisms explaining why music may facilitate social interactions. The model consists of three overlapping concepts: "who you are", "here and now", and "connectedness". When cognitive functions decline, music can help individuals maintain an identity and connection to their life history; by sharing the experience with other it can aid physical and emotional contact. The stimulating nature can orientate the individual to the present and allow self-expression. The adaptability enables activities to be inclusive through altering the complexity and involvement. Additional potential mechanisms for music facilitating interactions include music as cues and to regulate arousal when individuals are in a state of agitation, confusion, or disinterest (Allan, 2012; Ridder, 2003; Sixsmith and Gibson, 2007). McDermott's et al's. model (2014b) is a broad view of the mechanisms of music for individuals with dementia; the current review will explore in-depth the mechanisms highlighted in the model to gain insight into how music interventions in care homes may facilitate social interactions.



*Figure 2.1 McDermott et al's. (2014b) Psychosocial model of music in Dementia as presented in their paper which explores the importance of music to individuals with dementia.* 

Figure 2.2 presents a model developed by the authors to interpret the literature prior to the literature search. The model displays the author's theory development highlighting how music interventions may help facilitate social interactions. Element 1 developing a theory has guided the research question, literature search and inclusion criteria. For this review, music intervention will refer to any activity, active or passive, provided in care homes where the main element is musical. The activities could be provided by care staff, researchers, musicians, or music therapists. Social interactions will refer to exchanges between two or more individuals, including verbal and non-verbal communication and other social behaviours such as sitting together.



*Figure 2.2 A model developed by the primary researcher to interpret the literature prior to the literature search* 

### 2.2.2 Literature Search

A literature search was conducted from the earliest date available to March 2020 using the electronic databases Embase, Medline, PubMed, CINAHL, Cochrane library, Web of Science and PsycINFO on the 5th of March 2020. The search was re-run on the 22nd of July 2021. In addition, a hand search of included papers' reference lists was conducted. The following search terms were used:

• (Dement\* OR Alzheimer\* or Frontotemporal Dementia OR Lewy Body Dementia)

- (Music OR Music Therap\* OR Singing OR Sing OR Musical\*)
- (Interaction\* OR Social interaction OR Relationship\* OR Social exchange OR Communication OR Non-verbal\* OR Social behaviour OR Interpersonal interaction)

# 2.2.3 Eligibility Criteria

# Inclusion criteria

Articles were required to fulfil all inclusion criteria to be eligible.

• Adults aged 18+ with a diagnosis of dementia residing in care homes

• Studies focusing on care staff were included if the intervention involved the participation of residents

• The intervention's main element was musical, facilitated by care staff, musicians, researchers, or music therapists

- Reported outcomes of social interactions, relationships, or social behaviours
- Quantitative and/or qualitative methods, including- RCT, case studies, nonrandomised, observation, interviews, and before and after
- Written in English
- Published in a peer-reviewed journal

There was no restriction on gender, dementia type or severity

### Exclusion criteria

• Participants with mild cognitive impairment

• Studies conducted in the community or consisted of both community-dwelling and resident participants

• Systematic reviews, book chapters, theses, conference papers, opinion pieces and commentaries

## 2.2.4 Article Screening

After removing duplicates, articles were screened for eligibility in a two-stage process, title and abstract, then full text. Two reviewers (BW & LS) independently screened the articles and documented eligibility and exclusion reasons. Any discrepancies were discussed between reviewers, and unresolved discrepancies were resolved with a third reviewer (OM). Authors were contacted if papers were inaccessible.

# 2.2.5 Methodology Quality Check

The methodology quality of included articles was assessed independently by the two reviewers using the Downs and Black (1998) and Critical Appraisal Skills Programme (CASP) (2018) tools. These tools were selected on the recommendations from Deeks et al. (2003) and the Centre for Reviews and Dissemination (2009).

Downs and Black (1998) assessed randomised and non-randomised quantitative studies, consisting of 27 questions across five domains- reporting, external validity, internal validity (bias), internal validity (confounding), and power. For the current review, the item 'power' was removed. This was decided as none of the articles mention power, and the researchers followed the scoring system used in a similar published review article (McDermott et al., 2013). Some questions were not applicable to all study designs, and the maximum score varied accordingly based on design type. The maximum score achievable for: RCT- 27, repeated measures - 22, before and after – 22, and case studies -17. O'Connor et al.'s. (2015) Down & Black scoring was used but modified to account for nonapplicable questions due to study

design and removal of power, with excellent (25-27), good (19-24), fair (14-18), and poor (<14).

CASP (2018) assessed qualitative studies and consisted of ten questions with no scoring system. Both tools assessed mixed methods studies. Once again, discrepancies were discussed between the two reviewers and unresolved discrepancies were resolved by the third reviewer.

# 2.2.6 Data Extraction

The reviewers independently completed data extraction using a data extraction form created by the primary researcher. Data extracted included- title, authors, date, contact detail, country of origin, abstract, study design, aims, eligibility criteria, recruitment, sample size and characteristics, setting, intervention type and characteristics, facilitator, control, outcomes, measurement tools, statistical techniques, findings, and limitations. Any discrepancies were resolved through discussion between the reviewers.

# 2.2.7 Analysis

Initial descriptions of the findings were produced before concept mapping was used to highlight relationships between included studies. The researchers reviewed the extracted data and gave a keyword that represented each finding, such as nonverbal, group membership, and reminiscence. The keywords then formed themes; each keyword was written on sticky notes with the study reference. The researchers explored the assigned theme, and any keywords that covered the same theme but were worded differently were reviewed and assigned a more fitting theme name. Related themes were then grouped to identify relationships between studies. An overarching theme was created that represented the clusters of subthemes; these overarching themes were then used as the subheadings for the findings. Analysis was completed using A3 paper and sticky notes to visually move the themes around and see the relationships emerging between each study. It was decided that all studies would be included in the analysis despite methodology scores to highlight the quality of studies.

# 2.3 Findings

# 2.3.1 Narrative Synthesis Element Two: Developing a Preliminary Synthesis

The database searches retrieved 2069 results, and a further eight articles were retrieved during the hand search. In the database search re-run, an additional 320 articles were retrieved. During the screening stage, 102 discrepancies were recorded at the title and abstract level, 91 were resolved after discussions, and 12 with the third reviewer. Seventeen discrepancies were recorded at the full-text level, 15 were resolved after discussions, and two with the third reviewer. A total of 23 articles were included in the synthesis (Figure 2.3). Eight of the included articles used quantitative methods, which consisted of one controlled trial, four repeated measures and three before and after study designs. There was one mixed-method article consisting of an RCT and observational study design. The remaining 14 articles were qualitative methods consisting of interviews and observations. Table 2.1 presents the study characteristics of included studies.

# 2.3.2 Narrative Synthesis Element 4: Assessing the Robustness of the Synthesis

# 2.3.2.1 Methodology Quality

During the methodology quality check, 50 discrepancies were recorded on the CASP and 69 discrepancies on the Downs and Black tool. All discrepancies were resolved with the two reviewers.

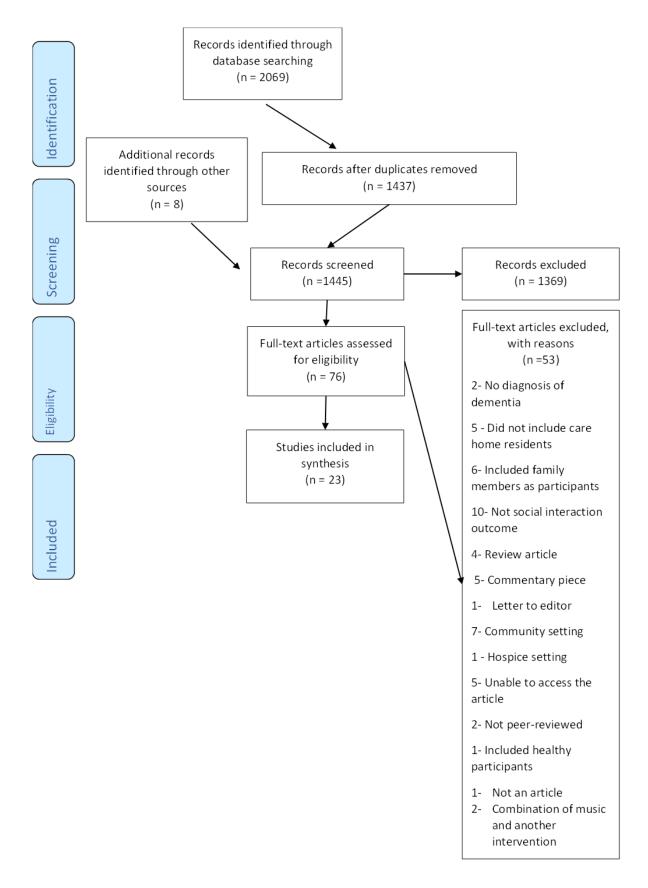


Figure 2.3 Included and Excluded articles including reasons for exclusion

In the Downs and Black tool, Engström et al. (2011a), Hsu et al. (2015), and Raglio et al. (2008) scored 'good'. The remaining quantitative studies scored between 'poor' and 'fair'. Clearly described aims, outcomes and participant characteristics were reported across all studies. All applicable studies reported adjusting for the difference in lengths of follow-up. Although some (42.9%) partially described confounding variables', Raglio et al. (2008) was the only applicable study to fully describe or adjust for confounding variables. Adverse effects were only reported by Hsu et al. (2015). From most articles, it was difficult to determine the sample and settings' representativeness due to poor reporting of eligibility criteria and recruitment strategy. The blinding of the outcome measures was only reported by Raglio et al. (2008). However, the nature of communication and observational data collection can make blinding the researcher challenging. All studies bar two documented adequate intervention reporting (Hammar 2012; Sambandham & Schirm, 1995). Sambandham & Schirm (1995) was the only study not to report the main findings adequately. It was difficult to determine whether outcome measures were accurate in three studies (Engstrom et al., 2011a; Lesta & Petocz, 2006; Pollack & Namazi, 1992) and the appropriateness of statistical analysis in three studies (Hammar et al., 2012; Raglio et al., 2008; Sambandham & Schirm, 1995). Raglio et al. (2008) did not use standardised randomisation.

Most of the qualitative studies scored reasonably high on CASP. Kydd (2001) and Ridder & Aldridge (2005) scored the lowest, with four out of ten. All studies were scored to have appropriate methodologies. Hsu et al. (2015) was the only study to report the recruitment strategy adequately. Clear aims were reported in 80% of the studies. Nine out of the 15 studies reported researcher-participant relationships inadequately. All studies bar Kydd (2001) reported clear findings. The reporting of methodology was insufficient in several studies, making it difficult to determine the appropriateness, including study design (Götell et al., 2009; Hammar et al., 2010; Hsu et al., 2015; Kydd, 2001 data collection (Dassa & Amir, 2014; Kuot et al., 2020; Kydd, 2001; Ridder & Gummesen, 2015), ethics (Hammar et al., 2011a; Kydd, 2001; Ridder

& Aldridge, 2005) and data analysis (Dassa & Amir, 2014; Kydd, 2001; Ridder & Aldridge).

### 2.3.3 Intervention Characteristics

Eight articles investigated music therapy (Dassa & Amir, 2014; Hsu et al., 2015; Kydd, 2001; Lesta & Petocz, 2006; Pollack & Namazi, 1992; Raglio et al., 2008; Ridder & Aldridge, 2005; Ridder & Gummesen, 2015) (Table 2.1). Music activities were explored in 15 studies that were facilitated by carers (Engström et al., 2011a, 2011b; Götell et al., 2002, 2009,2012; Hammar et al. 2010,2011a, 2011b, 2012; Kuot et al., 2020; Sambandham & Schirm, 1995; Swall et al., 2020), musicians (Campbell et al., 2017; Clare et al., 2019) or the researcher (Olderog Millard & Smith, 1989).

The layout and context of music activities varied across studies. Nine articles investigated MTC; however, only five unique separate studies and datasets were explored across the articles (Engström et al., 2011a, 2011b; Götell et al., 2002, 2009,2012; Hammar et al. 2010,2011a, 2011b,2012;). The MTC articles are all related, with papers published by one research team at the same university, with several articles being part of a doctoral research project. MTC consists of carers singing or humming, on an individual basis while completing tasks, including personal morning care, mealtimes, and personal transfer. Background music was also explored in some studies. Swall et al. (2020) explored incorporating music into daily routines. One study explored personalised music listening (Kuot et al., 2020).

The additional four studies explored group music sessions consisting of singing, music instrument playing or both. In Olderog Millard & Smith (1989), popular songs were sung while the researcher played the guitar. No details were reported in Sambandham & Schirm (1995), other than the intervention being facilitated by care staff. In Campbell et al. (2017), musicians provided music instrument improvisation sessions. Live music sessions were investigated in Clare et al. (2019), consisting of musicians and residents singing and playing instruments in group and individual interactions.

The music therapy studies were less inconsistent; they consisted of group sessions (Dassa and Amir, 2002; Lesta & Petocz, 2006), individual sessions (Pollack & Namazi, 1992; Raglio et al., 2008; Ridder & Aldridge, 2005; Ridder & Gummesen, 2015) or both (Kydd,2001), facilitated by a licenced music therapist. Hsu et al. (2015) had the additional element of indirect staff skill-sharing. Studies used a range of music therapeutic skills, including turn-taking, imitation, holding, containing, validation, empathy, and modelling. The residents' behaviours and needs mainly guided the sessions and, therefore, varied in activities, but singing, music listening, music playing, and reminiscence were all reported across studies.

## 2.3.4 Participant characteristics

#### Music activities

Campbell et al. (2017) and Swall et al. (2020) did not report any participants' characteristics, including the residents' sample size. Across the remaining studies, 97 residents were recruited aged 67-98. The studies that reported gender consisted of 27 females and 13 males. Age was not reported in four studies (Götell, 2012; Hammar et al., 2010, 2011a, 2011b), and gender was not reported in Götell et al. (2012), Kuot et al. (2020) and Sambandham & Schirm (1995). The dementia severity measures varied; however, all participants were reported to have moderate to severe dementia.

Eight of the studies included staff participants. Sambandham & Schirm (1995) did not report the sample size or characteristics. From the remaining seven studies, 79 participants aged between 20-63 were recruited. The studies that reported gender consisted of 53 females and two males. The names of staff job roles varied between studies, but all were reported to either be licensed nurses or carers. Engström (2011a) and Kuot et al. (2020) did not report age, gender, or job roles. Campbell et al. (2017) only reported interview numbers, which consisted of a music therapist, musicians, members of the organisation team, activity workers and a care home manager; age and gender were not reported.

# Music therapy

Across the studies, 98 residents participated aged between 64-97, consisting of 79 females and 19 males. Kydd (2001) did not report dementia severity; the other studies reported dementia severity between moderate to severe. One study consisted of ten carers aged between 21-60, with seven females and three males (Hsu et al., 2015).

# Table 2.1 Table with the author, year of publication, intervention, sample size and characteristic, study design and length of study presents the intervention type and characteristics.

Author (Year)	Country	Intervention	Control	Sample size (females)	Participant characteristic	Study design	Length of study
			Qualitati	ve Study Design			
Campbell et al.	UK	Music in Mind Programme	N/A	11 interviewed	1 Music therapist	Exploratory	Once weekly for
(2017)		Sessions provided by musicians		Number of	4 Manchester Camerata musicians	Qualitative	11 weeks
		to develop musical		session	2 intervention organisational team		
		improvisation. Access to		participants not	3 Activity workers		
		instruments.		provided	1 Cara harra managar		
		20-30 minutes.			1 Care home manager		
					Residents (not interviewed)		
					Resident characteristics not		
					reported		
					Interviewees' characteristics not		
					reported		
Clare et al.	UK	Music for Life Group	1 Recorded	8 Residents (4)	Mean age- 90	Qualitative	Once weekly for 9
(2019)		Active live music by musicians.	music listening		CDR between2.5 and 3.0		weeks
		Improvising singing and musical	C C				
		instruments playing.					

		1 hour.					
Dassa & Amir (2014)	Israel	Group music therapy Singing Israel songs from 1930- 1950. Conversations between songs to evoke memories and feelings. 45 minutes.	N/A	6 Residents (2)	Mean age- 79 MMSE between 7-20	Qualitative	Twice weekly for 1 month
Götell et al (2002)	Sweden	Music therapeutic care Condition 2- background music during personal morning care. Condition 3 - Carers sang during personal care. 6 to 22 minutes.	Usual morning personal care	10 Residents (8) 5 Carers (5)	Residents mean age- 84 years old MMSE between 0-12 Mean time at facilities- 3 years 1 month Carers- licensed practical or mental health nurses Mean age -29 years old Fluent in Swedish Mean time in geriatric care-10 years	Qualitative	Not reported

Götell et al.	Sweden	Music therapeutic care	Usual morning personal	9 Residents (7)	Residents-, MMSE mean 1,	Qualitative	Not reported
(2009)		Condition 2- background music	care	5 Care staff (5)	Mean time at facilities- 3 years 1		
		during personal morning care.			month		
		Condition 3- Carers sang during			Carers- licensed practical nurses or		
		personal care.			mental health nurses,		
		6 to 22 minutes.			All but 1 born in Sweden		
					Mean time in geriatric care- 10		
					years		
Götell et al.	Sweden	Music therapeutic care	Usual transfer	19 Residents	Resident- severe dementia	Qualitative	4- 5 days a week.
(2012)		Carers singing during personal		17 Carers	Age & gender not reported		4 weeks of
		transfer.		9 Carers	Carers – aged- 22- 55		control
				interviewed (8)	Worked in geriatric care- 1- 30		4 weeks of MTC
					years		
Hammar et al.	Sweden	Music therapeutic care	Usual morning personal	10 Residents (6)	Residents- age not reported	Qualitative	Once weekly for 4
(2011a)		Carers singing during personal	care	6 Carers (6)	MMSE mean -3.3		weeks
		morning care			Carer- aged- 31-54		
					4 nurse assistants, 2 nurse aids		
					Working in dementia care- 2.5- 30		
					years		

Hammar et al.	Sweden	Music therapeutic care	Usual morning personal	10 Residents (6)	Residents- age not reported	Qualitative	Once weekly for 2
(2010 & 2011b)		Carers singing during morning	care	6 Carers (6)	MMSE mean- 3.3		months
		personal care			Carers- aged 31-54		
					4 nurse assistants, 2 nurse aids		
					Employment at facility- 2.5- 30		
					years		
Ridder &	Denmark	1:1 music therapy	N/A	1 Resident (0)	Aged- 64	Explorative	Once weekly for
Gummesen		1:1 Singing, music playing and			Moderate to severe dementia	case study	14 weeks
(2015)		listening					
Kydd (2001)	Canada	Group and 1:1 music therapy	N/A	1 Resident (0)	88 years old	Case study	Once weekly of
		1:1 session - playing individuals			Dementia severity not reported		both 1:1 and
		chosen music, singing, piano					group session
		playing.					Length not
		30 minutes					reported
		Group sessions - weekly theme					
		using music and singing to					
		reminisces, exercise and					
		socialise.					
Ridder &	Denmark	1:1 music therapy	N/A	1 Resident (1)	Early 70s	Case study	20 sessions
Aldridge (2005)					MMSE score 0,		

		Therapist singing and skills			Time at facility- 10 months		
		including holding, containing,					
		validation and empathy.					
Kuot et al.	Australia	Personalised music playlist	N/A	10 Residents	Resident- mean 81 (67-93 years)	Qualitative	60 daily sessions
(2020)		Families provided a list of songs.		15 Carers	Gender not reported		
		Used an iPod device with			Staff characteristics not reported		
		headphones during the			Stan characteristics not reported		
		intervention.					
		30 minutes.					
Swall et al.	Sweden	Staff training in Music in	N/A	30 Carers (29)	Carers- aged 24-63	Qualitative	Daily for two
(2020)		Caregiving			Resident characteristics not		months
		lecture providing information on			reported		
		how to choose music for					
		caregiving, how to make sessions					
		person-centred and when to use					
		person-centred and when to use music. After the lecture, staff					

Hsu et al.	UK	1:1 Music therapy	N/A	17 Residents	Residents- mean age 84	Mixed	Once weekly for 5
(2015)		Interactive music therapy skills		(16)	GDS mean (intervention) - 5.89	methods	months
		including cueing, improvisation,		10 Carers (7)	GDS mean (control)- 5.50	clustered	
		and joint music-making.			, , , , , , , , , , , , , , , , , , ,	RCT	
		Instruments available. Talking for			Mean time at facility- 20 months.		
		reminiscence. Non-verbal			Carers - mean age 38		
		communication used to express			Employment mean- 32.33 months		
		cues.			(intervention) and 23.33 months		
		30 minutes			(Control)		

# Quantitative Study Design

Engstrom et al.	Sweden	Music therapeutic care	Usual morning personal	1 Resident (1)	Resident- 86 years old	A single	Once weekly for 8
(2011b)		Carers singing during personal	care	1 Carer	MMSE – 4	case AB	weeks
		morning care			Time at facility- 5 years.		
					Carers not reported		
Lesta & Petocz	Australia	Group music therapy	N/A	4 Residents (4)	Aged between 80-97	Before/	4 Consecutive
(2006)		Music therapist provided songs			MMSE <13	After	days
		to sing considering residents' sundowning.			Time at facility- minimum 5 months		
		30 minutes					

Olderog Millard & Smith (1989)		Group singing Researcher played the guitar while participants sang. 30 minutes	Discussion group researcher presented visual props to encourage group discussion. 30 minutes	10 Residents (7)	Mean age- 81.4	Reversal (ABABA) repeated measures	Twice weekly for 5 weeks
Pollack & Namazi (1992)		1:1 Music therapy Individuals preferred music activities- singing, moving, and playing instruments. Reminiscence. 20 minutes	N/A	8 Residents (5)	Mean age-76.8 MMSE mean- 7	Before/ After	Once weekly for a
Hammar et al. (2012)	Sweden	Music therapeutic care Carers humming during mealtimes. 15 and 21 minutes.	Usual mealtime care	1 Resident (1) 1 Caregiver (1)	Resident—Aged- 87 MMSE- 0 Time at facility- 16 years Carers- Aged- 51 years old Assisted nurse Worked in dementia care -31 years Time at facility- 6 years	ABA case study	Once weekly for five weeks.
Engstrom et al. (2011a)	Sweden	Music therapeutic care	Usual morning personal care	10 Residents (6) 10 Carers	Residents- mean age- 81.3 MMSE mean- 3.3	Repeated measures	4 Control session 4 MTC sessions

		Carers singing during personal			mean time at facility- 24.5 months		
		care			Staff characteristics not reported		
Sambandham &	USA	Group music sessions	N/A	19 Residents	Mean age- 83,	before/after	Twice weekly fo
Schirm (1995)		60 minutes no other information		Staff sample	MMSE mean- 7.1	7.1 6 weeks.	
		was given		size not	Gender not report		Each resident
				reported	Staff characteristics not reported		participated for weeks.
Raglio et al.	Italy	Music therapy	Educational and	59 residents	Mean age- 85.8 (control) and 84.4	Non-	16 weeks
(2008)		Non-verbal music therapy using rhythmical and melodic instruments to	entertainment activities	(50)	(intervention) MMSE - 10.7 (control) and 11.1	randomised controlled	3 cycles of 10 sessions
	promote intersubjective communication. 30 minutes	(personal care, lunch, bath,	(intervention)	trial			
			reading				
			newspaper, playing cards)				

# 2.3.5 Narrative Synthesis Element 3: Exploring the Relationships Within and Between the Studies

Many of the themes emerged from both music activities and therapy despite the difference in interventions. Table 2.2 presents a summary of the study findings.

## 2.3.5.1 Social Interactions Prior to the Intervention

Residents' social interactions prior to the intervention were explored mainly in MTC (Engström et al., 2011a, 2011b; Götell et al., 2002, 2009,2012; Hammar et al. 2010,2011a, 2011b,2012); and music therapy studies (Kydd,2001; Ridder & Aldridge, 2005; Ridder & Gummesen, 2015). During the studies, it was challenging to engage residents in positive interactions prior to the intervention, whether with staff, other residents, or family members. Many were isolated from social contact, leading to other issues such as depression.

In Kydd (2001), the participant remained in his room apart from at mealtimes and did not engage in communal activities or interactions. He could not follow the group format when attending only group music therapy, including selecting irrelevant songs and leaving before the end. In many studies, verbal communication was difficult for residents to use and comprehend. Some residents' verbal language consisted of repeating a single word or phrase (Ridder & Aldridge, 2005; Ridder & Gummesen, 2015). However, many of the participants across the studies were able to comprehend and use non-verbal communication. Ridder & Aldridge's (2005) participant was the only individual reported to have a disinterest in music prior to the session.

In the MTC studies (Engström et al., 2011a, 2011b; Götell et al., 2002, 2009,2012; Hammar et al. 2010, 2011a, 2011b, 2012), carers aimed to verbally narrate their actions, despite residents' inability to comprehend, leading to them repeating instructions. Carers used strong, energetic tones to portray warmth and enthusiasm; however, residents were confused and frightened, which was reflected in their speech. Residents' verbal communication was limited, and when used, was generally

a weak flat tone with monosyllables, incoherent speech and out of context sentences. Their primary forms of communication were muteness and 'resistance to care behaviours'. Carers referred to residents being physically present in the room but not mentally, making communication difficult and one-sided. However, researchers also reported that carers provided little opportunity for residents to interact actively. Both parties worked at different paces, leaving carers feeling lonely and powerless.

### 2.3.5.2 Residents' Social Interaction During and Post-intervention

The studies, despite intervention type, all reported changes in residents' interactions. However, the degree of change varied across the studies. Many reported increased sociable verbal and non-verbal communication while observing a decrease in unsociable verbal and non-verbal communication (Clare et al., 2019; Engstrom et al., 2011a, 2011b Götell et al., 2002, 2009, 2012; Hammar et al., 2010, 2011b, 2011a; Kuot et al. 2020; Kydd, 2001; Olderog Millard & Smith, 1989; Pollack & Namazi, 1992; Raglio et al., 2008; Ridder & Gummesen, 2015; Sambandham & Schirm.1995; Swall, 2020). Residents vocally participated more, and speech became more fluid and coherent. Verbal communication remained difficult for many residents; however, singing and music allowed them to express themselves. Even though residents were more capable of using non-verbal communication preintervention, the studies reported increased eye contact, smiling, and body movements. These improvements were reported to remain post-intervention. Participants were more sociable and interactive at other times of the day (Hsu et al., 2015; Kydd, 2001, Pollack & Namazi, 1992 Sambandham & Schirm, 1995), in turn reducing social isolation.

The increase in verbal and non-verbal communication was not significant across all studies. In Hammar et al. (2012), there was minimal change between usual care and MTC. However, argumentative, rejecting, and 'verbalising negative affection' were reported to diminish. The only recorded verbal communication used by the resident was humming in one session. In Lesta & Petocz (2006), the findings were more

inconsistent with all outcomes, both sociable and non-sociable, except reminiscence significantly improved overall. The post hoc tests highlighted that most outcomes, bar mumbling and wandering alone significantly improved during therapy compared to pre-therapy. However, mumbling, wandering alone, eye contact and talking were the only outcome to improve significantly post-therapy compared to during therapy. Additionally, significant improvements from pre- to post-intervention was only reported in mumbling, sitting alone, walking, and sitting with others. Some of these outcomes, such as sitting alone, may not demonstrate an improvement in social interactions; other factors may have affected the outcomes, such as seating availability. In Hsu et al. (2015), there was no significant difference in personal enhancers between conditions. Despite this, carers reported improvements in residents; in particular, one participant in Kuot et al. (2020) felt she was being buried alive when certain songs were played.

MTC orientated residents to the present and improved alertness, which may explain the improvements in fluency and coherency of speech as well as verbal communication comprehension (Engstrom et al., 2011a, 2011b Götell et al., 2002, 2009, 2012; Hammar et al. 2010, 2011b, 2011a). In both music therapy and music activities studies, an increase in laughter and humour between residents, staff, and other members strengthened connections and allowed residents to express positive emotions (Clare et al., 2019; Campbell et al., 2017; Engstrom et al., 2011a, 2011b; Götell et al. 2009, 2012; Hammar et al., 2010, 2011b, 2011a; Kuot et al. 2020; Ridder & Gummesen, 2015; Swall et al., 2020). In Dassa & Amir (2014), residents provided singing advice to other members, which aided in developing a collective identity. Music helped develop a sense of togetherness that facilitated socialisation and cooperation (Olderog Millard & Smith. 1989; Swall et al., 2020). In all music intervention types, residents were observed singing, even when verbal language was severely impaired (Götell, 2002, 2012; Hammar, 2010; 2011a, 2011a; Kuot et al., 2020; Lesta & Petocz, 2006; Olderog Millard & Smith, 1989; Ridder & Gummesen, 2015; Swall et al., 2020). The ability to sing and remember lyrics improved self-

esteem and confidence, encouraging communication through music (Dassa & Amir, 2014). In Swall et al. (2020), some participants were unable to sing; however, they were able to have reciprocal communication without verbal language through movement and shared music experiences. Residents who display agitated behaviour, even when interacted with verbally, relaxed and calmed when music was introduced, providing a time and space for residents and facilitators to communicate through music and non-verbal communication (Hsu et al., 2015; Ridder & Aldridge, 2005; Ridder & Gummesen, 2015). Ridder and Aldridge's (2005) participant was the only individual to have little reaction to the intervention due to her impairments; however, touch was still observed as a form of communication that aided the development of a relationship between the therapist and resident.

### 2.3.5.3 Staff Experience

Some studies consisted of care staff as facilitators or participating members (Campbell et al., 2017; Clare et al., 2019; Engstrom et al., 2011a, 2011b; Götell et al., 2002, 2009, 2012; Hammar et al., 2010, 2011b, 2011; Hsu et al., 2015; Swall et al., 2020). Staff were made aware of small non-verbal signals which had previously been missed or misinterpreted (Campbell et al., 2017; Clare et al., 2019). As a result, staff could alter their communication style to accommodate the resident. Through reminiscence and meaningful interactions, staff gained greater insight into residents' lives and personalities, allowing them to see the identity behind the diagnosis (Campbell et al., 2017; Clare et al., 2019; Hsu et al., 2015). In the MTC studies, staff reported relationships and interactions as one-sided and limited, if not completely non-existent, during usual care (Engstrom et al., 2011a, 2011b; Götell et al., 2002, 2009, 2012; Hammar et al. 2010, 2011b, 2011a). Through music, a mutual understanding was developed, with staff reporting more reciprocal relationships where both parties were actively engaging. The reciprocal nature of interactions during music was also explored in Swall et al. (2020). Improvements in communication skills were observed in both residents and staff. The care staff in Swall et al. (2020) became more aware of interactions, allowing them to adapt them to be more person-centred and meaningful. Staff felt that music allowed them to provide instructions more gently and respectfully. In the MTC studies, staff increased

their non-verbal communication and reduced verbal language (Engstrom et al., 2011a, 2011b Götell et al., 2002, 2009, 2012; Hammar et al. 2010, 2011b, 2011a). The researchers highlighted the paradoxical findings but suggested fewer instructions were required due to improved awareness and interactions. Therefore, tasks were completed more effectively without the need for intense narratives. The addition of the staff skill-sharing in Hsu et al. (2015) allowed staff to include effective music interaction skills into daily practices, ensuring that benefits remained post sessions.

### 2.3.5.4 Mechanisms of Music for Facilitating Social Interactions

The articles highlighted potential mechanisms of music that could facilitate social interactions, which were observed in both music therapy and music activities. The primary researcher developed a model to visually highlight their interpretation of the analysis of findings from the original papers outlining the potential mechanisms for facilitating social interactions (Figure 2.4). Although the aims and context of music therapy and music activities varied, the mechanisms were present in both intervention types to some degree.

The interventions were not based on cognition or verbal language, which allowed residents to engage without their impairments hindering their experience. Adaptability allowed interventions to be tailored to residents' needs and abilities, making them inclusive for all, despite dementia severity. Music was highlighted as an alternative communication form for residents to express themselves when verbal language deteriorates. The use of musical turn-taking and mirroring allowed residents to be actively involved in interactions and build relationships (Clare,2019; Ridder & Gummesen, 2015). Improvisation allowed participants to create something together as equal partners, strengthening connections (Campbell et al., 2017; Clare et al., 2019; Kydd, 2001; Ridder & Gummesen, 2015). Sessions provided a safe space for residents, staff and/or facilitators to communicate without intentions, expectations, or defined outcomes. Staff learnt it was acceptable to allow interactions to occur naturally. During periods of silence, staff discovered

interactions were still occurring, with residents' psychological, social, and emotional needs still being met (Clare et al., 2019; Campbell et al., 2017). A safe space was crucial for those residents usually uncomfortable with communicating. In Campbell et al. (2017), the musicians were attuned to the residents' vulnerability, which enabled them to alter the environment and interactions, such as being aware of more subtle communication cues, as well as knowing when residents needed stillness and silence.

Music acted as a cue to orientate to the present, with residents becoming more aware of their surroundings, and improving interaction's fluidity and coherence. A prominent theme was reminiscence. Music from the residents' earlier years evoked personal memories that allowed for discussions around life stories (Hsu et al., 2015; Campbell et al., 2017; Dassa & Amir, 2014; Götell et al.,2002; Kuot et al., 2020; Lesta & Petocz, 2006; Pollack & Namazi, 1992; Sambandham & Schirm, 1995; Swall et al., 2020). The music in Dassa and Amir (2014) revolved around cultural or historical events, which evoked patriotism, leading to the development of a sense of belonging.

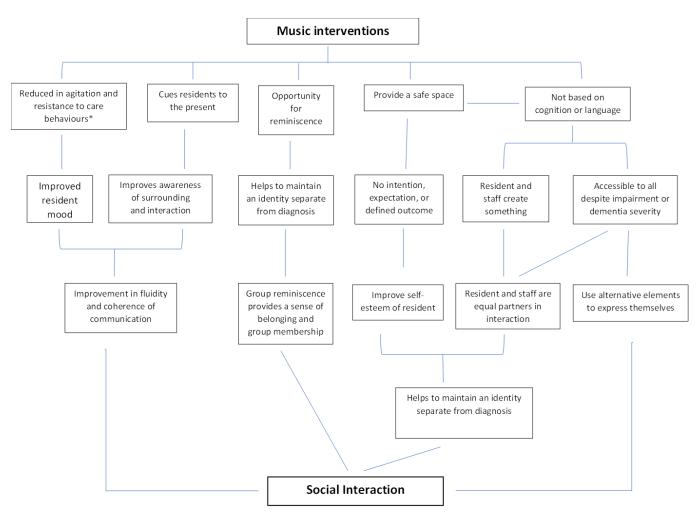


Figure 2.4 The model highlights the authors' interpretation of the result that highlights the potential mechanisms to explain how care home music interventions can facilitate social interaction. The lines highlight the connection the authors have made between the mechanisms. Many of the mechanisms were highlighted in both music therapy and music activities. \*Reduction in resistance to care was seen in the studies where music was used during care tasks and Reduction in agitation was seen in all music interventions.

Table 2.2 Table with the outcomes each study explored, the data collection methods used, a summary of the key findings and the methodology quality check findings.

Author (Year)	Outcomes (data collection methods)	Summary of findings	Methodology Quality Check (not reported items)
		Qualitative Studies	
Campbell et al. (2017)	Participation Experience (Interviews & diary entries)	<ul> <li>Allowed residents to make choices and develop relationships</li> <li>Improved awareness</li> <li>Staff gained insight and understanding of the resident and their abilities</li> <li>Staff learnt different types of communication styles. Learnt to allow interactions to happen naturally, and it is okay to be together in silence</li> <li>Residents used music to express themselves</li> </ul>	CASP-9 /10 (Care home and participant recruitment)
Clare et al. (2019)	Nature and range of interaction changes in communication skills (Video observation)	<ul> <li>Live music facilitates both verbal and non-verbal communication</li> <li>Communications is a network of subtle and complex interactions with no linear form, creating a multisensory environment</li> <li>Interactions required the initial communicative action to be noticed by another member and for them to respond</li> <li>If communicative action were missed, residents cease communication attempt</li> </ul>	CASP- 9/10 (Care home, and participant recruitment)
Dassa & Amir (2014)	Connection between musical features and conversation topics (Video observation)	<ul> <li>Two types of conversations- 1) relating to the context of the song, 2) relating to the activity of group singing</li> <li>Songs evoked memories of their country or personal events</li> <li>Members provided advice on singing to other members, Providing a sense of belonging.</li> <li>Paid compliments to other members.</li> </ul>	CASP-7 /10 (Recruitment) Insufficient reporting of data collection methods & data analysis methods

(2002)(Video observation)Despite decreased verbal communication, residents understanding increased.Res(2002)Silenced residents became more talkativeunderstanding increased.un	
(2002)       (Video observation)       increased.       Residents' verbal communication became clearer and more mutual.       (Ai         Silenced residents became more talkative       MTC interactions were mutual.       (Ai         MTC interactions were mutual.       Reminiscence       (Canopi)         Götell et al.       Communicating emotions and mood       Control condition- cares conveyed friendliness, warmth, and engagement through an energetic voice       Control condition- Residents had weak flat, monotone voices.       Un         (2009)       (Video observation)       Communication was fragmented and short       application was fragmented and short       application         Intervention condition- residents more vocal, with both residents and staff, speaking with a warm tone       Interactions were more equal       pai         Verbal communication was not always necessary to express emotions.       Residents playfully responded to carers       Both parties connected physically and emotionally with mutual appreciation expressed.         Götell et al.       Communication       Singing improved the efficacy and ease of a task       Canopication       Singing improved the efficacy and ease of a task       Application         Götell et al.       Linterview)       Residents had increased awareness, making communication easier       Application       Application         Götell et al.       Linterview)       Residents had increased enhanced positive moods and emotions	SP-8/10
Götell et al.       Communicating emotions and mood       Control condition- cares conveyed friendliness, warmth, and engagement through an energetic voice       CA         (2009)       (Video observation)       Control condition- cares conveyed friendliness, warmth, and engagement through an energetic voice       Un         (Video observation)       (Video observation)       Communication easing mented and short       application         (Video observation)       Intervention condition- residents more vocal, with both residents and staff, speaking with a warm tone       Or speaking with a warm tone       (Ai         (Ai       Nersense       Softell et al.       Communication       CA         (2012)       (Interview)       Enhanced mutual verbal and non-verbal communication easier Both parties expressed enhanced positive moods and emotions       CA         (2012)       (Interview)       Enhanced mutual verbal and non-verbal communication easier Both parties expressed enhanced positive moods and emotions       CA         (2012)       (Interview)       Residents had increased awareness, making jokes and laughing       rei	cruitment strategy
Götell et al.Communicating emotions and mood (Video observation)Control condition- cares conveyed friendliness, warmth, and engagement through an energetic voice Control condition- Residents had weak flat, monotone voices.Un communication was fragmented and shortDi apple(Video observation)Intervention condition- residents more vocal, with both residents and staff, or speaking with a warm tone(Ai Interactions were more equal Verbal communication was not always necessary to express emotions.paiGötell et al.CommunicationEnhanced mutual verbal and non-verbal communication expressed.CAGötell et al.CommunicationCA Singing improved the efficacy and ease of a taskCA(2012)(Interview)Residents had increased awareness, making communication easier Both parties expressed enhanced positive moods and emotionsApBoth parties expressed enhanced positive moods and emotionsrecIncreased humour, with residents making jokes and laughingrec	ms)
<ul> <li>Intervention condition- residents more vocal, with both residents and staff, or speaking with a warm tone (Ai parties connected physically and emotionally with mutual appreciation expressed.</li> <li>Communication</li> <li>Enhanced mutual verbal and non-verbal communication easier Ap Both parties expressed enhanced positive moods and emotions</li> <li>Residents had increased awareness, making communication easier Ap Both parties expressed enhanced positive moods and emotions</li> </ul>	SP- 6 /10 able to determine
<ul> <li>Interactions were more equal</li> <li>Interactions were more equal</li> <li>Verbal communication was not always necessary to express emotions.</li> <li>Residents playfully responded to carers</li> <li>Both parties connected physically and emotionally with mutual appreciation expressed.</li> <li>Enhanced mutual verbal and non-verbal communication</li> <li>Communication</li> <li>Cantage (Interview)</li> <li>Enhanced mutual verbal and non-verbal communication</li> <li>Singing improved the efficacy and ease of a task</li> <li>Residents had increased awareness, making communication easier</li> <li>Both parties expressed enhanced positive moods and emotions</li> <li>Increased humour, with residents making jokes and laughing</li> </ul>	propriate study desi recruitment
Götell et al.       Communication       Enhanced mutual verbal and non-verbal communication       CA         (2012)       (Interview)       Enhanced mutual verbal and non-verbal communication       CA         Both parties expressed       Singing improved the efficacy and ease of a task       Ap         Image: Solution of the so	ms & researcher and ticipant relationshi
Gotell et al.       Communication       CA         (2012)       (Interview)       Singing improved the efficacy and ease of a task       Ap         • Residents had increased awareness, making communication easier       Ap         • Both parties expressed enhanced positive moods and emotions       rec         • Increased humour, with residents making jokes and laughing       rel	
(2012)       (Interview)       • Residents had increased awareness, making communication easier       Ap         • Both parties expressed enhanced positive moods and emotions       rec         • Increased humour, with residents making jokes and laughing       rel	SP- 8/ 10.
	propriateness of ruitment strategy a
	ationship between earcher and ticipants determined
Hammar et al.Carer's experience of communionControl condition- communication was difficult or impossible Residents were physically in the room but not mentally presentCA	SP-9/10

	/ <b>F</b> )	Carers felt alone in the task and communication.			
	(Focus group)	Residents did attempt to show love through touch	(Recruitment strategy)		
		<ul> <li>Intervention condition- communication was more mutual, with residents</li> </ul>			
		more aware and present.			
		Improvement in residents' speech			
Hammar et al.	Communication	Control condition- carers did not invite residents to participate in the communication	CASP- 8/10		
(2011a)	(Video observation)	Little eye contact from either party	Insufficient reporting of		
		<ul> <li>Carers and residents attempted to interact at different paces.</li> <li>Intervention condition- increased eye contact, and residents could actively engage more as both parties attempted to interact at the same pace.</li> </ul>	the recruitment strategy and ethics		
Hammar et al.	Verbal and non-verbal	<ul> <li>Control condition- carers used non-verbal communication to act out tasks but rarely invited the residents to join in the task or interaction.</li> </ul>	CASP- 7/ 10		
2010)	communication	Little eye contact from either party	Unable to determine th		
	(Video observation)	<ul> <li>Carers and residents worked at different paces, residents were slower, and carers regularly interrupt</li> </ul>	appropriateness of stud design and recruitment		
		Intervention condition- carers invited residents to communicate more	strategy is appropriate.		
		<ul> <li>Increased non-verbal communication elements became the primary form of communication</li> </ul>	(Researchers and participants'		
		Eye contact and humour increased	relationship)		
Ridder &	Communication	Resident struggled to understand verbal communication, had limited verbal language, repeated a single phrase			
Gummesen	(Video recording,	He did understand and use non-verbal communication	Unable to determine th		
(2015)	Therapist log, pre- assessment reports, session transcripts)	<ul> <li>He used the drum app on the iPad to explore sounds and engage in rhymical playing</li> <li>Singing, turn-taking, and mirroring were used to connect</li> </ul>	appropriateness of recruitment strategy an data collection		
		He used different tones of voice and gestures to express himself	(Researcher and participant relationship		

		<ul> <li>The joint sing helped develop a symbolic relationship leading to the resident feeling safe.</li> </ul>	
Kydd (2001)	Social interaction (Direct observation)	<ul> <li>At the beginning, he was reluctant to play his banjo as he felt he was not as good as he used to be</li> <li>He struggled to follow group music session rules and would leave early</li> <li>As sessions progressed, participation increased with him following rules</li> <li>He became more sociable at other times of the day by increasing interactions with others</li> <li>During the sessions, he would reminisce and performed for the other residents.</li> </ul>	CASP- 4 /10 Unable to determine the appropriateness of recruitment strategy Insufficient reporting of ethics, data collection and clear findings (Researcher and participants' relationship)
Ridder & Aldridge (2005)	Behavioural effects of music (Video recording, modified Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1986), music therapist log)	<ul> <li>Challenging to engage the resident in positive interactions due to serve dementia</li> <li>Prior to sessions- isolated from social contact with staff and residents</li> <li>During sessions- She used touch to connect and pulled the therapist up from the sofa to walk with her a sign of mutual understanding.</li> <li>She repeated a single word, and the use of the word increased</li> <li>The resident did not actively participate in sessions</li> </ul>	CASP- 4 /10 Unable to determine the aims, researcher and participant relationship, the appropriateness of study design, recruitment, ethics, and rigorousness of analysis
Kuot et al. (2020)	Behaviour, well-being, clinical management, culture, and social interaction (Focus groups)	<ul> <li>The intervention did not work for all residents.</li> <li>Music improved social interaction with staff and other residents</li> <li>Staff more playfulness with residents</li> <li>Reduction in resistance to care behaviour</li> <li>Music is a conversation point</li> </ul>	CASP- 7/10 Unable to determine the researcher participant relationships, the appropriateness of

			recruitment and data collection
Swall et al. (2020)	Feeling behaviours of residents and carers (World café discussion)	<ul> <li>Intervention built bridges in a person-centred way to connect with residents</li> <li>Interactions more valuable, joyful, and meaningful, created opportunities to frame reciprocal communication</li> <li>The intervention promoted togetherness that facilitated socialisation and cooperation</li> <li>Promoted communication when language was no longer available.</li> <li>Singing was a respectful way to reach the residents.</li> <li>Music helped develop life stories for the resident and start discussions.</li> </ul>	CASP- 9/10 Unable to determine the appropriateness of recruitment
		Mixed Methods	
Hsu et al. (2015)	Carers and residents' interactions (Interview, video observation, Dementia Care Mapping (Brooker & Surr, 2006), Neuropsychiatric Inventory (Cummings et al., 1994))	<ul> <li>Case study- musical vocal, bodily and facial expressions were used as emotional cues.</li> <li>The therapist's verbal expression agitated the resident, but soothing melodies were used as musical cues when verbal failed.</li> <li>The resident used eye contact and smiling in interactions</li> <li>The resident reminisced over playing the piano; this was fed back to staff use in routines.</li> <li>Quantitative study- Personal enhancers did not differ between the intervention and control group at 3 months (-24.08 95% CI [-97.47 to 49.32] P=0.294), 5 months (-28.08, 95% CI [-86.70 to 30.55], P=0.176) or 7 months (-18.83, 95% CI [-37.68 to 0.026], P=0.050).</li> <li>Carers reported improvement in mood, communication, self-expression, and agitation in the intervention group.</li> <li>Carers gained insight into residents' life history and Improved interaction, communication, and relationships</li> </ul>	CASP- 8 /10 Unable to determine the appropriateness of study design (Researcher and participant relationship) Downs & Black- 19 /26

		Quantitative Studies	
Engstrom et al. (2011b)	Social and unsocial communication behaviours (Video observation, modified Verbal & Nonverbal Communication Scale (Williams, 2017))	<ul> <li>Significant improvement in 5 of the 9 sociable verbal communication behaviours includes coherent (t= -2.295, p&lt;0.012) and relevant communication (t 975) = 2.726, p=0.009), humming (t (75) =3.032, p=0.004), singing (t (75) =4.43, p=0.0005), and responding to questions (t (75) =-5.17, p=0.0005).</li> <li>Residents' ability to respond to questions increased by 69% (baseline mean 1.53) (intervention mean 4.95).</li> <li>Unsociable non-verbal communication decreased by 80%, including cursing (t (75) = -2.14, p=0.037) and not responding to questions (t (75) = -4.92, P= 0.0005). Cursing only significant unsociable verbal outcomes to decrease out of 5 outcomes. Does not respond to questions, only unsociable nonverbal outcome to significantly decrease out of 7 outcomes.</li> </ul>	Downs and Black - 9 /1
Lesta & Petocz (2006)	Mood, social behaviour, and non-social behaviour (Mood-behaviour Assessment Chart. (Author designed tool))	<ul> <li>Improved non-social and social behaviours</li> <li>All variables apart from reminiscence significantly improved- mumbling (0.002), sitting alone (0.001), wandering along (p= 0.0011), walking with others (0.009), sitting with others (0.001), eye contact and smiling (p&lt;0.001), talking (p&lt;0.001).</li> <li>Social behaviours increased from pre- to post-therapy, with eye contact and smiling (P=0.22), and talking (P=0.52) being non-significant and walking with others (P=0.030) and sitting with others (p= 0.005) being significant</li> </ul>	Downs and Black- 11 /
Olderog Millard & Smith (1989)	Social behaviour, vocal participation (Behaviour Mapping Observation (Ittelson et al., 1970), Bell and Smith	<ul> <li>Significant difference between pre-and post-intervention in sitting (F (4,36) = 3.131, P= 0.0262) and walking together (F 9(4,36)- 3.129, P= 0.0263).</li> <li>Singing condition- significantly higher vocal participation (F (4,36) = 4.435, P=0.0051)</li> <li>Both conditions significant effect on residents' behaviour</li> <li>Smiling increased during the session and touching other increased post-session.</li> </ul>	Downs and Black- 12 /

	Checklist (Bell & Smith, 1986))		
Pollack & Namazi (1992)	Social and non-social behaviour, participation (Direct observation, individual observation form, Behavioural Checklist)	<ul> <li>24% increase in social behaviours and 14% decrease in non-social behaviours post sessions. (x<sub>2</sub>= 14.2, df=1, P&lt;0.001)</li> <li>The most significant increase in social behaviour was non-verbal, which increased from 32% to 68%</li> <li>Increase in verbalisation and positive verbal feedback</li> <li>Reminiscence was present</li> <li>Residents' interactions becoming more fluent</li> </ul>	Downs and Black- 9 /19
Hammar et al. (2012)	Verbal and non-verbal interactions Facially expressed emotions (Video observation, Verbal, and Nonverbal Interaction Scale (Williams 2017), Observed Emotion Rating Scale (Lawton, 1996))	<ul> <li>Eye contact decreased in the second baseline and intervention sessions</li> <li>The resident could not verbally interact, which stayed consent across sessions</li> <li>Resident hummed in one session</li> <li>Carers' interactions remained the same, but verbal communication decreased</li> </ul>	Downs and Black- 8 /20
Engstrom et al. (2011a)	Social and unsocial communication behaviour (Video observation, modified Verbal, and Nonverbal Interaction Scale (Williams, 2017))	<ul> <li>Sociable verbal and nonverbal communication increased by 23% from 209 observations (mean-26.1) to 258 (mean- 32.3)</li> <li>Unsociable verbal and non-verbal communication decreased by 80% from 30 (mean- 3.8) to 6 (mean-0.8)</li> <li>The Resident asked appropriate questions more frequently</li> <li>Increased smiling and laughing</li> <li>Residents' language was more coherent but still challenging to understand</li> </ul>	Downs and Black- 13/ 21

Sambandham & Schirm (1995)	Communication, social skills, capacity to reminisce (Glynn's Music Therapy Assessment Tool (Glynn, 1992), direct observation)	<ul> <li>Significant difference in verbal behaviour</li> <li>Residents used more verbal and non-verbal communication in the 20 minutes post-session</li> <li>Participants displayed predictable patterns of improvements in alertness, verbal or non-verbal interactions or energy. (Statistics not provided)</li> </ul>	Downs and Black - 6 /21
Raglio et al. (2008)	Empathetic behaviour, Nonempathetic behaviour, smiling, body movement (Music Therapy Coding Scheme (Raglio et al., 2006))	<ul> <li>Improved empathetic behaviours (f3,87=.10.37, p&lt;0.0001; Cohen d= 0.61)</li> <li>Reduction in non- empathetic behaviours (f (3,87) =5.55, P=0.0015; Cohn d=1.8)</li> <li>Smiling (f (3,87) = 8.14, p&lt;0.0001) and body movements (f (3,87) = 12.41, p&lt;0.0001 increased</li> <li>Enhanced communicative relationship between resident and music therapist.</li> </ul>	Downs and Black -20/25

#### 2.4 Discussion

Twenty-three papers were included in the final synthesis, which consisted of music activities and music therapy. Although the music interventions differed in their approaches and purpose, overall studies reported increased residents' sociable verbal and non-verbal communication and decreased unsociable communication.

In the findings, elements two, three and four of the narrative synthesis were explored. Once the data was extracted, an initial synthesis of the findings (Element 2) was completed to gain an understanding of the effects of the interventions. The initial synthesis was expanded to identify the relationships within and between the studies (Element 3). Element Three allowed the researchers to explore why and how interventions facilitated social interactions and the barriers and enablers that may have impacted the effectiveness. Within the result section, the researchers also assessed the methodology quality of the included studies, which contributed to the first stage of assessing the robustness of the synthesis (Element 4). In the discussion, the researchers will further explore the relationships between the included studies (Element 3) with reference to other published studies to contextualise the findings. The robustness of the synthesis (Element 4) will be assessed further by exploring the limitations of the included studies and the limitations of the review itself.

Music therapy and music activities explored in this review highlighted similar mechanisms to explain how care home music interventions facilitate social interactions, including providing an opportunity to reminisce, providing a safe space and being inclusive for all. Although the findings have highlighted similar mechanisms, it has been argued that music activities cannot substitute music therapy. McDermott et al. (2018) argue that music interventions rely on the delivery of the intervention and the facilitator as much as the intervention content. Music activities are generally provided by staff, musicians, or volunteers, who have less musical training than music therapists and, therefore, may struggle to provide highquality interventions. Additionally, the aims of music therapy and music activities vary; therefore, the intervention best suited for the resident will be dependent on

their needs. Although music activities cannot substitute music therapy, there is a need for them within care homes, and this review highlights their benefits. The findings from this review suggest a range of activities can be facilitated by either care staff or musicians that provide similar benefits to music therapy in facilitating social interactions. These findings are promising for UK care homes because access to music therapy is limited by funding and therapist availability (Schneider, 2018). Some form of music activity could be accessible to all care homes to help facilitate social interactions. However, a recent report suggests that only 5% of residents have access to high-quality arts and music interventions (Bamford & Bowell, 2018).

The findings suggest music can improve social isolation, alertness, moods, connecting with others, self-worth, maintaining an identity and ability to express themselves. Many UK residents could be potentially missing out on these benefits, leading to lower quality of life and care and increased BPSDs. Lack of staff time and workload pressures have been highlighted as limiting factors in delivering music activities (Ekra & Dale, 2020; Stanyon et al., 2016; Sung et al., 2011). However, the MTC studies highlighted that staff-led musical interactions could be provided without additional time or workload burdens and without compromising on the quality of physical care. Staff also reported that care tasks were completed more efficiently, quicker, and calmly because residents showed increased awareness and communication comprehension.

The studies highlighted music accessibility to all individuals with dementia, although factors such as dementia severity and residents' needs may influence engagement. Interventions were all adaptable to be inclusive, allowing different abilities to actively engage with the intervention, either on their own or with other residents at the same time. The slightest engagement, such as eye contact or touch, was reported beneficial. Social interactions are vital for humans, even when they may be unable to equally reciprocate the communication (Moyle et al., 2013). The findings also recognised Kitwood's (1998) theory of personhood. Interventions aimed to meet residents' fundamental needs beyond physical health and safety, leading to

improved communication, behaviour, and well-being. Although the studies in this review imply that residents' needs were considered to guide the intervention, Hackett et al. (2021) argue that many music interventions lack individual goals. Instead, a single goal is assigned to all individuals in the intervention despite their differences, which could affect the effectiveness of facilitating social interactions.

The findings supported McDermott's et al. (2014b) psychosocial model that music can facilitate social interactions by allowing individuals to maintain their identity and connect with others. Residents used music to connect with staff, discovering the identity behind the diagnosis. In group sessions, residents connected by discussing joint experiences such as cultural and historical events, creating a sense of belonging. Although some studies highlighted group membership, participants' culture, traditions and/or country of research may impact the sense of belonging. In Dassa & Amir (2014), although the participants had diverse cultural backgrounds, all grew up in Israel and may have had similar experiences. In larger diverse countries such as the USA or the UK, residents may have vastly different experiences; thus, reminiscence may not create a sense of group membership. If some residents' country of origin differed from where they currently live, the opposite effect might be observed if the activity focuses solely on traditional music. When Sonas, an intervention developed and implemented in Ireland, was researched in the UK, the Irish songs and poetry were not altered. The British participants with dementia had no familiarity with the songs (Hutson et al., 2014). The lack of connection with the songs and poetry may explain the lack of clear benefits that had previously been found in Ireland. The Sonas' study suggests that music should be personalised to the individual and in line with their culture and group identity.

The discussion of barriers to successful implementation was limited among studies. Campbell et al. (2017) argued that contextual, structural, and organisational considerations could impact music interventions in care homes. The care staff's attitudes are a primary necessity for successful implementation. The ability to be flexible and adaptable to the residents' needs, moods, and health was also necessary

(Hsu et al., 2015; Kuot et al., 2020). In Kuot et al. (2020), between 4-10% of sessions were missed due to sleeping or unwillingness to attend; flexibility in start time could improve attendance rates. Additional time from care staff may be required to provide support when dementia symptoms make accessing music interventions challenging, such as forgetting about sessions. As mentioned previously, staff are limited by available time, making accessing training and implementing interventions difficult (Boersma et al., 2015; Hsu et al., 2015; Keenan et al., 2020; Lawrence et al., 2012). In Hsu et al. (2015), despite staff's positive attitudes, the skill-sharing element was challenging to implement due to staff shortage and time pressures. High staff turnover can also impact implementation, as new staff require training (Kuot et al., 2020). In the studies, staff had little singing experience and may have felt embarrassed; more training in singing and using music could be a positive enabler to successfully implementation into practice (Götell et al., 2009, 2012).

# 2.4.1 Narrative synthesis Element Four: Assessment of the Robustness of the Synthesis

### 2.4.1.1 Limitations of Studies

A significant limitation of the studies was limited follow-up data collection, with studies only collecting data during or immediately after the music intervention. The lack of longitudinal studies indicates difficulties in determining the longer-term effects of music on social interactions, which has also been highlighted by previous systematic reviews (Van der Steen et al., 2018; Vink et al., 2003). However, Hackett et al. (2021) argue that the mechanisms of music interventions would not achieve a longitudinal effect after the intervention ended. Instead, music should be provided in daily dosages to maintain regular benefits.

Interview studies omitted collecting data from residents. While it can be challenging to collect data directly from individuals with dementia, there is a missed opportunity to gain insight from the residents' perspective. Previous research highlights differences in perception of residents' well-being, care and health between residents and care staff (Buckley et al., 2012; Griffiths et al., 2020). Therefore, the interview

studies portray a carer's perception of social interaction in care homes rather than an accurate representation of residents' interactions.

The first author was involved in the study and analysis stage for many studies; this could lead to a 'Researcher effect' with preconceptions influencing their analysis. Discussions with other researchers were used to overcome this issue. Similarly, in the music therapy studies, many therapists were also the researcher, which could have impacted the therapist's behaviour during sessions and the researcher's behaviour during analysis. Dassa and Amir (2014) reported this issue when the roles of music therapists and researchers conflicted. Similarly, Lesta & Petocz (2006) reported that observers became quasi-group members when issues arose with residents, leading to bias issues and a lack of internal validity and reliability.

## 2.4.1.2 Limitations of Review

The included articles were all written in English from peer-reviewed journals. As a result, articles may have been excluded that could provide greater insight into facilitating interactions through music. The decision to omit non-peer-reviewed articles could have led to this review displaying publication bias. The researchers wanted to create a transparent and rigorous review. However, with limited resources and the review being required for a time-limited project, it was decided only to include peer-review journal papers.

The quality of this review relies on the quality of the study's methodology. It was decided all studies would be included to highlight the quality of current music interventions; however, due to the lower methodology quality, the findings should be interpreted with caution. The limited reporting of music intervention in some studies made it difficult to highlight relationships between studies and determine potential mechanisms for how music interventions facilitate social interactions.

#### 2.4.2 Practical Implications

This systematic review has highlighted that introducing music activities into care homes could benefit most residents, despite the severity of their dementia. The interventions could improve verbal and non-verbal communication, provide insight to staff on the person behind the diagnosis, and improve social participation and task efficacy. Furthermore, staff-led interventions highlighted the plausibility for staff with no music training to implement music skills. The most appropriate intervention will vary between care homes, and several factors influence the appropriateness, including finances, availability of facilitators, residents' preferences, needs, and abilities. In the staff-led interventions, many lacked the confidence and knowledge to implement music interventions. If interventions are not high-quality, they could lack efficacy or be harmful (McDermott et al., 2018). Therefore, there is a need to develop an accessible and standardised manual to ensure that implemented staff-led music interventions are high-quality. Alternatively, a combination of music therapy and staff skill-sharing, as present in Hsu et al. (2015), could enable staff to incorporate music into care with a music therapist's support to ensure the benefits continue outside of the music therapy sessions. The combination of music therapy and staff skill-sharing has been explored in McDermott et al. (2018). Residents can continue to communicate when verbal communication deteriorates. However, care professionals need to recognise residents' alternative communication behaviours and respond appropriately.

## 2.4.3 Future Research

The included articles had low to medium methodology quality. Therefore, future research should focus on improving methodology quality in music intervention studies. Reporting the intervention process in more detail will ensure that research can be replicated and successfully implemented. Although briefly mentioned, future research should consider the barriers and enablers to successfully implementing care home music interventions. The findings of MTC highlighted the potential of singing during care to improve interactions; however, as the articles were produced by the same research team and consisted of five studies, the data should be considered with caution. Future research into MTC is required to ensure the findings are

replicable. Finally, residents were passive participants in the research process. Future research that invites residents to attend interviews could produce valuable insight into their experience.

### 2.4.4 Conclusion

There is evidence that both music therapy and music activities can facilitate social interactions for people with dementia in care homes. Residents displayed increased verbal and non-verbal communication and interacted more with carers, music therapists, session leaders, and other residents. Benefits were not exclusive to those with sufficient verbal communication abilities; many participants with language impairments were observed singing. For those with no language, the sessions were still inclusive by using non-verbal communication, suggesting that music can benefit a wide range of residents with dementia. Finally, the findings only highlight increased communication during or immediately after the music intervention; as previous research highlights, regular, continuous dosages of music rather than a one-off intervention would ensure benefits remain. Quantitative studies provided inconsistent findings, with many exploring social behaviour in an unconventional way, such as walking together, rather than communication and interaction outcome. This may have been due to the subjective nature of interactions or the lack of tested standardised outcome measures for social interactions. Standardised outcome measures were used in some studies, however, many had to be modified, and the Verbal and Non-Verbal Interaction Scale had not been tested at the point of use (Williams, 2017). This review highlights a potential need to develop quantitative outcome measures that are more fit to measure social interactions in individuals with dementia.

# 3. Manual Development

## 3.1 Introduction

The systematic review highlighted that music therapy and music activities have similar mechanisms that could explain how they facilitate social interactions. Both interventions provided an opportunity to reminisce, provided a safe place to explore and express themselves and were inclusive for all residents regardless of dementia severity or impairments. Although music therapy and music activities consist of similar mechanisms when implemented, music activities may be of a lower quality due to the difference in training provided for staff and musicians compared to music therapists (McDermott et al., 2018).

Music therapy generally considers the delivery of the intervention, focusing on how the facilitator interacts with the client as well as the content of the session (McDermott et al., 2018). Whereas many music activities' training focuses more on the content over the delivery. However, the promising results from the systematic review highlight the plausibility for staff to facilitate music activities that produce similar benefits to music therapy, implying that there should be a focus on developing a training tool to provide staff with not only the skills and knowledge of music activities but also provides knowledge on "being" with the resident, similar to the interactions provided in music therapy. Music therapists' use of music therapy skill-sharing has begun offering staff the opportunity to develop their skills, however, without a standardised manual, the training varies between therapists and is limited to care homes in a position to employ a music therapist. Additionally, many staff in the staff-led interventions felt they lacked the knowledge and confidence to implement them, therefore, a manual which focuses on providing staff opportunities to gain confidence and experience with the support from experts could increase the quality of music activities used within care homes.

The systematic review highlighted the plausibility of incorporating music into other tasks minimising the additional time and work burden for staff. The results from the MTC studies reported in the systematic review suggest that to increase staff

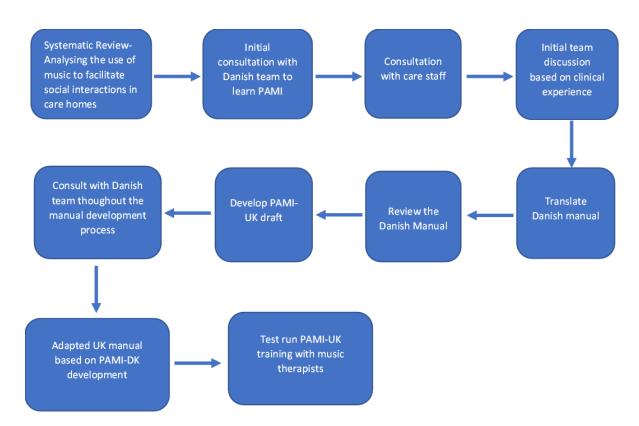
engagement, motivation, and the likelihood of successful implementation and longterm continuous usage, the music skill-sharing manual should imbed music into other tasks. Additionally, the systematic review results highlight that to maintain benefits, regular daily doses of music are required compared to structured on-off sessions. Embedding small doses of music into staff daily routines could increase the likelihood of them providing music daily compared to more structured music sessions which may be dropped from schedules in favour of other tasks when time is limited. Flexibility was highlighted as a facilitator to implementation in Chapter 2, which was not only vital to ensure staff availability to facilitate sessions but also for providing the interventions at convenient times for residents to increase participation. Embedding the music into routines would allow for this flexibility to occur as the activities would not require planning. The results from Chapters 1 and 2 highlight that a standardised staff-training manual could ensure that care homes provide highquality staff-led music interventions that will benefit residents and staff.

PAMI-DK was a seven-year project funded by the Velux Foundation and Danish Alzheimer Society Research Foundation that aimed to develop and evaluate an evidence-based training manual to be used by music therapist to educate carers in using nonverbal communication with people with dementia (Ridder et al., 2022, 2023). PAMI provides staff with a range of music skills traditionally reserved for music therapy. Staff gain awareness of their behaviours and discover how music and musical elements can be incorporated into daily interactions to allow staff and residents to experience attuned interactions that attend to residents' psychological, social, and emotional needs. The results from the systematic review guided the development of the UK PAMI to ensure that the training tool is suitable for UK care homes with the barriers and limitations from previous research being considered.

## 3.1.1 Manual Development Process

PAMI was originally developed by a team at Aalborg university, Denmark (PAMI-DK) (Ridder et al., 2022,2023), however as highlighted in previous research (Hutson et al., 2014), adaptation is required when planning to implement interventions in a

different country to its origin. This PhD intended to develop a UK version of PAMI (PAMI-UK) which is culturally appropriate for UK care home. During the manual development process, the primary researcher completed several stages: systematic review, expert consultations, translation, development, and alteration prior to investigating the intervention in care homes (Figure 3.1).



*Figure 3.1 Flow diagram outlining the manual development process for the development of the PAMI intervention UK version* 

## 3.1.1.1 Translation and Cultural Adaptation

The translation and cultural adaptation of a psychosocial intervention can be complex as it requires a systematic modification of the intervention (Werheid et al., 2021). Cultural adaptations rely on the consideration of language, culture, and context to ensure that the intervention aligns with participants' cultural patterns, meanings, and values. As a result, proven efficacy of the intervention in one culture does not guarantee the same efficacy in the new culture. As highlighted with the Irish Sonas intervention when it was introduced into England without reviewing the Irish songs and poems (Hutson et al., 2014). The first stage of translation and cultural adaptation should be exploring the cultures and values of the original and the adapted country to determine how their differences may impact the intervention. There are two frameworks generally used to adapt interventions. The theory-based top-down approach uses the efficacy of previous research to translate the manual to another language or determines the adaptation in advanced and pilot the adapted manual in one study (Werheid et al., 2021). The second framework is a community-based bottom-up approach that involves working with stakeholders to determine the needs of the intended users and determine cultural considerations (Hwang et al., 2009; Werheid et al., 2021). A combination of top-down and bottom-up approaches should be adopted in cultural adaptations to ensure that an intervention is developed that accommodates the needs of the intended audience while also based on evidence-based theory (Barrera et al., 2013). Several adaptation frameworks have been developed to guide intervention developments (Barrera & Castro, 2006; Hwang, 2011; Kumpfer et al., 2008; McKleroy et al., 2006), with many similarities between frameworks.

PAMI-DK was initially developed to be used in Danish dementia care; therefore, the first stage of developing PAMI-UK was considering the cultural differences between Danish and UK care homes that may impact the intervention.

### 3.1.2 Danish Care System

Denmark is considered to have one of most comprehensive long-term care system in Europe (World Health Organization Regional Office for Europe, 2019). Older people in Denmark are encouraged to remain living independently for as long as possible, with a range of services available to ensure this can occur including extensive home help and nursing care. Even when individuals may need to enter a care home, provisions are in place to ensure that individuals can maintain some level of independence and control in their life (Healthcare DENMARK, 2018). In 2018 approximately 1,132,000 individuals lived in some form of long-term care facility in Denmark (World Health Organization Regional Office for Europe, 2019). Many of the care homes have a home-like atmosphere where residents are considered tenants,

with a range of additional services available (Healthcare DENMARK, 2018). Residents pay rent for their room and any additional services from their pension, which is supplemented by the government for those with a low income. The country spends 2.2% of its Gross Domestic Product (GDP) on the care of its older citizens.

## 3.1.3 Differences Between the UK and Denmark

Several cultural differences between the UK and Denmark could impact care homes in the two countries. The Danish culture is known for its strong sense of tradition and history, which results in a strong national identity, creating a sense of community and solidarity (Støvring, 2012; Ostergard, 1992, 2004). The Danish identity represents an identity between the state, nation, and society, with Danes having high levels of trust (Støvring, 2012). In comparison, the UK is a multicultural nation that is not only diverse between the four countries (England, Wales, Scotland, and Northern Ireland) that make up the UK but also has a strong history of migration from other countries, leading to the culture from other countries and religions being introduced to the UK (Vertovec, 2006; Office for National Statistics, 2021).

Denmark has a strong emphasis on social equality and unbalanced social hierarchy, which has a direct impact on the structure and delivery of social care in the country, although, in practice, there is more economic inequality among Danes (Heckman & Landerso, 2021; Merrild, 2017). Social care is considered a fundamental right for all Danish citizens, meaning all individuals should have access to essential services regardless of socioeconomic status or background (Denmark.dk, 2023). In Denmark, older adults are encouraged to remain in the community for as long as possible, with the government providing free home care services to aid long-term independence (Healthcare Denmark, 2018). Danish care homes are seen as more integrated into the community; there is a strong focus on social connections and community engagement, encouraging all members of society to participate in social and cultural activities (Health Investor, 2018). In contrast, UK care homes are more on the edge of the community, with some homes encouraging participation between the care home

and the rest of the community through activities, while others remain entirely separate from the rest of the community.

A central concept in Danish culture and lifestyle is Hygge, which does not directly translate to English (Wiking, 2016). The concept aims to capture the essence of cosiness, comfort, and well-being. Hygge emphasises appreciating time spent with loved ones to create a feeling of unity. Hygge is about being present in the moment and appreciating the simple things in life. Hygge is intertwined with the Danes lifestyle and, therefore, could influence care homes. Care homes in Denmark are designed as real homes to give residents a sense of ordinary living and familiarity (HealthCare Denmark, 2019). Hygge strongly emphasises togetherness and social connections, which could explain why care homes are intentionally designed to include communal spaces to allow residents to socialise, share meals, and engage in conversation during mealtimes (HealthCare Denmark, 2019). Kofod, 2012).

In the UK, 90% of care homes are privately owned, whereas in Denmark approximately 93% of care homes are owned publicly (Health Investor UK, 2018; Knight Frank, 2018; Quince, 2013). Although more private care homes are opening in Denmark resulting from a change in legislation. Denmark has higher tax rates compared to the UK; however, this allows for high-quality, free health care, with all care homes charging a similar rate (Health Investor UK, 2018). Whereas in the UK, fees vary greatly, with the cost impacting the quality and available facilities. In Denmark, many care homes are modern purpose-built facilities, with individuals receiving a two-room unit. The resident's personal space generally consists of a living room, bedroom, bathroom, and a small kitchenette, a mandatory design feature to allow individuals to maintain some independence when entering long-term care (Health Investor UK, 2018). Many care homes encourage residents to bring their own furniture. In the UK, residents are encouraged to bring personal items to make their room more homely. However, in Denmark, residents are encouraged to bring larger furniture items such as armchairs (Smith, 1983).

One significant difference between the UK and Denmark is the technology used within care. Denmark digitalised all social care data in 1995 (Health Investor UK, 2018). In contrast, the UK is in the process of digitalising data currently, with this varying between care homes. All health and care data are digitalised to one platform MedCom (Danish Centre for Health Telematics) which allows for efficient information sharing between health care professionals to ensure integrated care. A platform called Sekoia (Sekoia, 2023), has been introduced into some Danish care homes to improve the access of care notes, record residents' preferences and enable residents to listen to their preferred music in their rooms. Although PAMI-DK does not rely on technology, the technology in Danish care homes has improved task efficiency and ensures consistency between carers and shifts, which has the potential to influence other interventions, such as technology reducing time and staff burden, which in turn allows staff more time to interact socially with residents.

Finally, another significant difference between Denmark and UK is the care culture (Health Investor, 2018). In the UK, care homes are heavily regulated, with CQC or Scotland and Wales's equivalent assessing care standards, care home visitors signing in and out, and residents having restricted freedom of activities and access to care home areas. In Denmark, there is a higher level of trust with Denmark lacking a regulatory body similar to CQC. Local authorities regulate public care homes, but private care homes have even more flexibility. Therefore, the system relies on selfregulation, and trust that the care home and staff will treat residents with dignity and respect. Many Danish care homes have facilities, such as libraries and gyms, available to both residents and the public. Although this encapsulates immense trust in the public, the format allows residents to remain an integral part of the community, unlike in the UK, where residents can feel confined, isolated, and excluded. The differences highlighted may influence care staff and residents' acceptance of PAMI and impact implementation. While there are a number of differences between Denmark and UK care homes there are also a number of similarities including the lack of available time, under pressure and being undervalued (Balkin et al, 2023).

There are also differences in the singing cultures in Denmark and the UK that may influence PAMI and, therefore, require consideration during the manual development process. Denmark has a strong community singing identity (Fællessang), which Danes find is important in good and bad times as it creates a national identity (Redohl, 2021). During WW2 and COVID-19, Fællessang created a sense of national solidarity. During COVID-19, several community singing sessions were regularly broadcasted nationally, with 1/5th of Danes participating. As Fællessang is an integral part of Denmark's society, the Folk High School Songbook has been created containing the songs used regularly in community singing (Ministry of Foreign Affairs of Denmark, 2020). The UK does not have the same strong community signing identity, potentially due to the UK being larger and more diverse, resulting in multiple signing communities that the UK's rich history has influenced. The UK has a strong tradition of choral music, in particular, religious cathedral choirs (Cathedral Music Trust, 2022), opera (Royal Opera House, N.D.) and musical theatre (Gordon et al., 2016). UK music artists have a global influence on the music scene from various genres, including classical, folk, pop, rock, Britpop, and Northern Soul.

#### 3.1.4 Differences Between the Countries that Constitute the UK

As PAMI-UK aims to be culturally appropriate for all the UK, it is important to consider the cultural differences between the four countries (England, Northern Ireland, Scotland, and Wales) that constitute the UK. The variations in the four countries could potentially influence PAMI-UK, and the different cultures should be displayed in the resources to enable the intervention to be tailored and used in care homes in all four countries.

Modern Scotland has a strong connection to Scottish traditional music, including folk songs, fiddle music and bagpipes, with music displaying Celtic connections (Byrne, 2011). It has been highlighted that music significantly influences the sense of national identity among Scottish people, with songs such as 'Flower of Scotland' creating a sense of pride and passion when sung at sporting events. It is common in Scotland to participate in Ceilidhs to celebrate Scottish culture and signify a community meeting

to share songs, stories, food, and drink (Sheridan & Byrne, 2008). Music is considered important in the Scottish curriculum, with elements being included to promote traditional Scottish music studies (Byrne, 2011). This musical curriculum in many parts of the country involves learning traditional instruments, including the chanter, bagpipes, clarsach, fiddle, whistle, bodhran and Gaelic and Scottish songs. In Scotland, the Gaelic language is still preserved, especially in the highlands and islands, and expressed through songs that encourage a strong sense of Scottish identity (Byrne, 2011). The participants in Byrne's (2011) study highlighted a blending of Scottish culture with new music genres and other cultural influences from around the world.

While Wales speaks predominantly English, the country still has a strong connection with the Welsh language, with 29% of the population speaking Welsh (Llywodraeth Cymru, 2023); therefore, the Welsh language plays a role in the Welsh music culture (Barlow, 2015). Wales has a strong choral tradition, with the tradition of male voice choirs in coal-mining communities being well-known (Schutz, 2020). Welsh people have a strong love of singing rooted in folklore (De'Ath, 2016). Music is so embedded in the Welsh culture that Wales has been coined "The Land of Song" (Schutz, 2020). Over the years, musicians have been influential in developing the Welsh identity through music and arts (Ifan, 2022; Jones, 2008). Eisteddfodau is a key part of the culture, a competitive cultural festival consisting of music and poetry that dates to at least 1176 (De'Ath, 2016). In many parts of Wales, people identify with smaller neighbourhoods rather than with towns or the country (Jones, 2008). Jones (2008) argued that Wales has not had the political unity that Scotland has previously experienced. However, there has been a move towards exploring the Welsh identity.

Ireland has a deep-rooted history of conflict based on religion and identity, which plays a significant role in Northern Ireland's culture. Music plays a role in identifying the differences in identity between the separations in Ireland (Cooper et al., 2009). Within the protestant community, some individuals distance themselves from traditional Irish music, such as using the Uilleann pipes and the bodhran, as they

perceive these as associated with the catholic community and culture of the Republic of Ireland. Instead, individuals may associate more with Scottish or British folk songs. However, some individuals have changed their attitude towards traditional music in recent years.

England does not have as strong of a connection with traditional folk music as Scotland, Ireland, or Wales, as it has been more influenced by modernisation than the other countries. However, a collection of musicians and academics have been promoting the reintroduction of the 'English Voice' (Owen, 2016). English folk music forms an English identity through the idea that the rural landscapes are a place to discover and contain individual creative inspiration and emotional expression. More recent genres are also argued to influence the English identity, with the notion of "Englishness" being applied to bands such as The Beatles, the Kinks and Blur (Cloonan, 1997).

While each country that makes up the UK has deep-rooted folk music traditions, in today's society, most individuals listen to a range of music genres based on personal preference rather than national identity. In 2018, 70% of British adults listened to pop music, with R&B and dance being the second and third most listened-to genres at 45% each (Statista, 2018).

Finally, as mentioned previously, the UK is a multicultural country, and therefore, the workforce and residents in care homes are also culturally diverse (Office for National Statistics, 2021; Skills for Care, 2020). During the PAMI-UK training, staff must be reminded to tailor the intervention to the resident's cultural needs, which may differ from the UK. A section in the manual was added to highlight to care staff the importance of considering a resident's nationality, religion, and countries they may have lived in prior to the UK, as these can influence the music used. The section also highlights that the music and culture an individual relates to may not necessarily be from the country where they were born. Therefore, the care staff should work with

residents and families to determine the residents' identity rather than make assumptions.

# 3.1.5 Manual Development Aims

- Conduct expert consultations with care staff on their care home and current practices to aid with manual development.
- 2. Translate the Danish manual into English and determine require changes to ensure cultural appropriateness.
- 3. Develop PAMI-UK based on the Danish manual and expert consultations.

# 3.2 Methods

# 3.2.1 Medical Research Council (MRC) Guidelines

The research team identified PAMI-UK as a complex intervention, therefore the Medical Research Council (MRC) guidelines have been followed to aid the researchers in designing, running, and reporting PAMI-UK (Craig et al., 2008). Complex interventions are interventions consisting of several interacting components. They may be complex for several reasons including the number and difficulties of behaviours of those receiving the treatment, facilitator requirements, number and variability of outcomes, degree of flexibility to tailor the intervention, or number of groups targeted.

The framework consists of four phases (Figure 3.2) - Development, Feasibility and piloting, Evaluation, and Implementation. Completing all four phases is outside the scope and time restraints of the PhD, instead this PhD focused on the Development phase and began to explore the Feasibility and piloting phase. Although the project does not fully explore all four phases they have been considered during the designing of the intervention, to ensure that future studies can focus on the Feasibility and piloting, Evaluation, and Implementation stages.

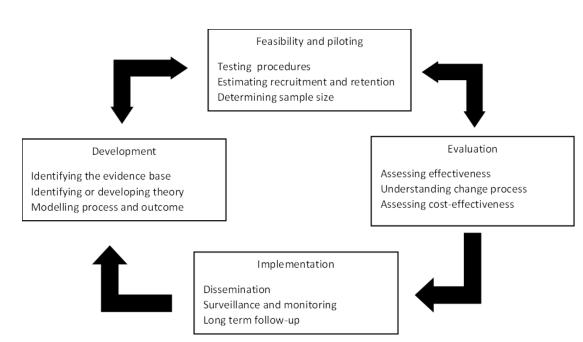


Figure 3.2 MRC Guidelines for researching Complex Interventions

## 3.2.2 Cultural Adaptation Framework and Procedure

The manual development stage was conducted between December 2019 and September 2021. During this time, the research team translated the PAMI-DK resources before adapting and developing a UK version of the intervention. The research team returned to the development stage in January 2022 to make amendments based on the field-testing study. The researchers took an integrated theory-based top-down and community-based bottom-up approach, where the team explored the cultural adaptation and needs of UK care homes and staff through consultations before translating and adapting the PAMI-DK resources. Papers that investigated cultural adaptation in other psychosocial interventions were reviewed to guide the PAMI-UK adaptation (Aguirre et al., 2014; Tol et al, 2018; Werheid et al., 2021). Since the MRC guidelines do not provide guidance on culturally adapting complex interventions, a framework specialising in cultural adaptions was also followed. Two frameworks that guided the adaptation were the Formative Method for Adapting Psychotherapy (FMAP) (Hwang, 2009) and Barrera & Castro (2006). Two frameworks were explored as the FMAP was originally developed for psychotherapy rather than psychosocial interventions in general, while the Barrera & Castro's framework did not provide sufficient detailed guidelines. However, both frameworks follow a similar process.

The FMAP framework consists of five phases:

- 1) Generating knowledge and collaborating with stakeholders
- Integrating generated information with theory and empirical and clinical knowledge
- Reviewing the initial culturally adapted clinical intervention with stakeholders and revising the culturally adapted intervention
- 4) Testing the culturally adapted intervention
- 5) Finalising the culturally adapted intervention

The Barrera and Castro Framework consists of four phases:

- 1) Information gathering
- 2) Preliminary adaptation design
- 3) Preliminary adaptation tests
- 4) Adaptation refinement

The manual development stage consisted of six phases (Figure 3.3); research and consultations, translation, adaptation, development, testing, and amendments. The first phase of FMAP: generating knowledge and collaborating with stakeholders correlated to phase one of the manual development where the researchers collaborated with both the Danish PAMI team and care staff in UK care homes. FMAP phase two also correlates to the first phase of the manual development where the researchers explored the feedback collected from the care staff and Danish team and considered it in relation to the research teams' clinical experience, previous research and the systematic review presented in Chapter 2. FMAP's phase two led into phase three, four, and five of the manual development where the Danish manual was translated, adapted and the UK PAMI was developed. Once the manual was developed the researchers returned to the Danish team to review the adapted intervention (FMAP phase three). FMAP phase three correlates to the manual development and evaluation studies (Chapter 5 and 6). At the end of each study, the manual was revised based on care staff's feedback. Phase 4 is testing the culturally adapted intervention, this phase will begin in the manual evaluation study (Chapter 6), to obtain preliminary data on the effects of PAMI-UK on staff and residents. However further testing of the culturally adapted manual would be required to determine the efficacy, which sits outside of the scope of this project. Phase five also sits outside the scope of this project. Figure 3.4 highlights the different individuals involved in the manual development process.

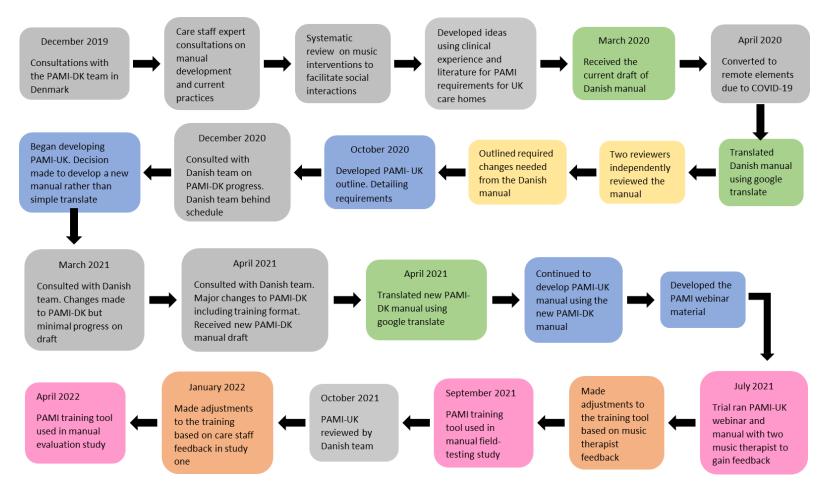
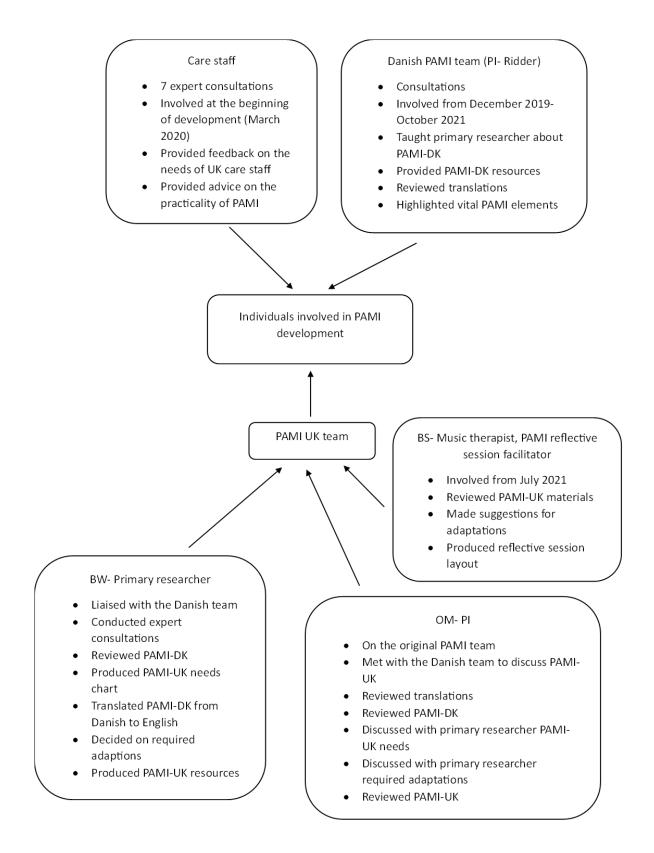


Figure 3.3 A flow diagram displaying the stages of the manual development process. Boxes coloured grey report the research and consultation stages. Green boxes report the translation stage. Yellow boxes report the adaptation stage. Blue boxes report development stage. Pink boxes are testing the manual and orange are the alteration stages.



*Figure 3.4 Mind map highlighting the three groups of people involved in the development of PAMI-UK* 

#### 3.2.3 Initial Exploration and Expert Consultation

The first step was consultations with the Danish PAMI team and care staff to gain insight into PAMI and care home's needs. At this stage, the researchers also considered their own care home clinical experience and reviewed how their experience may influence PAMI-UK development.

## 3.2.3.1 Consultation with the Danish Team

At the beginning of the research project, the Danish and UK research teams initiated a collaboration. Discussions between the two teams have continued throughout the project to ensure that PAMI-UK contains the ethos, principal, and vital components of PAMI while also adapting to meet the needs of UK care homes. The first meeting occurred in December 2019, where the primary researcher was introduced to the PAMI-DK resources. The meeting provided a greater understanding of the PAMI concept and manual and allowed both parties to outline their expectations for the translated and adapted intervention. At the time of the first meeting, the PAMI-DK was still in development. The team had a first manual draft and had begun running initial training sessions with music therapies but continued developing the training tool based on feedback received. The initial meeting allowed the UK team to gain insight into the current stage of the PAMI-DK and consider the components that would need to be adapted for UK care homes.

### 3.2.3.2 COVID-19

Between meeting with the Danish team in December 2019 and beginning the expert consultations with staff, the COVID-19 pandemic began leading to national restrictions in the UK. At this stage in the project the research team decided to make changes to the manual development process and overall study design to accommodate the restrictions, which enable the team to continue developing PAMI-UK. COVID-19 resulted in the closure of ethics committees and university, and attention was diverted to COVID-19 research, as a result the research team used their professional networks to conduct expert consultations to gain initial insight into the needs of care homes, as these did not require formal ethical approval. The COVID-19 pandemic resulted in some delays in the study due to having to make

significant alterations to some areas of the project. Additionally, as COVID-19 was a global pandemic the Danish team experienced challenges and delays which subsequently affected the PAMI-UK development. (More in-depth discussion on COVID-19's impact on the manual development and project is available in 3.4.1 COVID impact on manual development, Chapter 7, and Appendix 5).

### 3.2.3.3 Expert Consultation with Care Staff

The research team started expert consultations with care staff at the beginning of the COVID-19 pandemic (March 2020). The researchers aimed to involve care staff early in the project to ensure that the manual was appropriate and practical for use in UK care homes. However, the researchers had restricted access to care homes and limited available channels to engage with staff due to the national COVID-19 guidelines.

When the COVID-19 Lockdowns began in March 2020, the research team were in early discussions on incorporating public and Patient Involvement (PPI) and expert consultations into the manual development. The researchers aimed to include a range of stakeholders to ensure that PAMI-UK targeted different stakeholders' priorities. Although in the early stages of discussions, initially, it was planned that the primary researcher would work with several care homes to gain a greater understanding of the care homes' needs in relation to the PAMI-UK training. The primary researcher would have spent time building relationships with the care homes, residents, staff, managers, and residents' families, allowing the researcher to have regular discussions with each stakeholder to determine their priorities and needs for the PAMI-UK intervention. The researcher would have also regularly attended the care home to observe routines to determine the best ways to seamlessly incorporate the PAMI-UK training and skills into current practices. As it can be difficult for individuals with later stages of dementia to communicate, there was also the potential possibility for the researcher to attend the Institute of Mental Health (IMH) PPI group at the University of Nottingham to speak to individuals with dementia and their families who are living in the community. This opportunity would

have allowed the researchers to gain insight into what individuals with dementia would like to see from the PAMI-UK intervention from a group that could potentially need residential care in the future.

When the pandemic began, external visitors were unable to attend care homes. Therefore, the primary researcher could not attend care homes to observe practices. In the first three months of COVID-19, there were high stress levels, poor staff mental health, uncertainty over COVID-19 policies, high COVID-19 rates, poor working conditions, and Personal Protective Equipment (PPE) shortage (The Queen's Institute, 2020). Therefore, many managers and staff did not have the time or capacity to participate in the expert consultations, especially not to the extent originally planned. Not being able to attend care homes also restricted the researcher's access to speak with residents.

At the start of the COVID-19 pandemic, many care homes were unprepared for the move to more technology-based interactions, with many homes having outdated technology systems with limited access for staff and residents, therefore reducing the amount of access the researchers could have remotely with care homes (Chu et al., 2021b; Khowaja et al., 2023). The researchers were unaware at the time whether residents could share their experiences and ideas via conference calls. Additionally, speaking to residents via conference calls would have made the discussions a more formal interview style rather than the informal conversations the researchers initially planned.

Having restricted access to care homes subsequently meant that the researcher was also unable to identify family members of residents who could share their experiences and views. Similarly, many organisations and groups that would help the researchers identify PPI members, such as the IMH PPI group, also temporarily closed until they could organise remote meetings. As the development of the manual was time-sensitive to ensure sufficient time to evaluate it, it was decided to find methods

that could be conducted immediately, even though this meant being unable to gain the views of most of the stakeholders.

Instead of the initial plan, the primary researcher advertised the consultations through social media, mainly activity coordinator forums in which the primary researcher belonged to due to their previous role as a well-being therapist (Appendix 1). A questionnaire was sent via email or Facebook Messenger (Meta Platforms, Inc) to interested care staff (Appendix 2). Email and Facebook Messenger were used to enable staff to complete the document at a convenient time without adding additional burden whilst managing the pandemic.

### 3.2.3.4 Systematic Review

The researcher completed a systematic review (Chapter 2) on current music interventions in care homes to gain an understanding of successful and unsuccessful elements of care home research and music interventions. This understanding ensured that PAMI-UK was not a repetition of previous interventions and provided insight into the previous research's limitations and barriers. The information collected aided the development of the PAMI-UK tool and study design to ensure that the intervention and study were appropriate for implementation in care homes.

### 3.2.3.5 Initial Team Discussion

Based on previous research, the researchers' clinical experience, staff feedback, and discussions with the Danish team; the first stage of the manual development was to determine the needs of the UK version. Initial ideas were generated highlighting the purpose and needs for PAMI in UK care homes. The researchers discussed which PAMI-DK components were essential and which needed altering to improve cultural appropriateness for the UK. The aims, principles, and practical elements were discussed by considering the staff feedback, the teams' clinical experience and the systematic review (Chapter 2).

#### 3.2.4 Translation

The UK team received the first PAMI-DK draft in March 2020. However, the Danish team continued developing and adapting the training based on feedback from sessions with Danish music therapists. PAMI-DK is written in Danish therefore the first stage of the manual development was to translate the resources into English. Some of the resources contained materials, such as videos, that could not be shared with the UK team due to consent and GDPR laws, meaning in some areas the UK team had little material to work with. The PAMI-DK first draft consisted of a 16-page workbook containing both theory and reflective activities and an accompanying PDF containing 111 slides used during the training sessions. The PowerPoint (Microsoft) contained theory, reflective activities, and videos highlighting the PAMI skills in greater detail.

The PAMI-DK manual and PowerPoint were translated from Danish to English using Google Translate (Alphabet Inc). Once translated into English, the primary researcher reviewed the resources to ensure accurate translation in relation to the context of the document. Incoherent words were searched to determine alternative meanings that made the sentence coherent. The final translation step was to send the documents to the original team in Aalborg university, who spoke both Danish and English, to ensure correct translation without essential PAMI elements being mistranslated or lost in translation.

In December 2020, the UK team consulted with the Danish team for an update on their manual development. They were behind schedule owing to COVID-19 and maternity leave; therefore, the UK team did not receive the updated resources until April 2021. The second draft of PAMI-DK consisted of a music therapist teaching manual and updated staff workbook. The teaching manual consisted of a 44-page booklet containing instructions on running the training sessions and completing the reflective activities. The updated staff workbook consisted of a 16-page booklet (

Table 3.1). The same translation process was used for the second draft.

#### Table 3.1 Changes made in the second version of PAMI-DK, March 2021

#### Changes in PAMI-DK updated staff workbook

- Table signposting the elements of training, including what skills would be learnt
- Reduced the theory quantity and complexity
- Simplified some reflective activities. For example, the activity that reflects on the individual's musical voice parameters
- Change the order that information is presented
- Explained the elements more clearly and in more depth
- Provided more practical elements, for example, providing songs that could be used
- Simplified the music care plan

#### 3.2.5 Adaptation

After the translation stage, two researchers (BW & OM) independently reviewed the resources documenting areas that needed altering to make PAMI more usable and appropriate for UK care homes. The two researchers had different backgrounds; one was a music therapist, while the other had a background in mental health with experience as a well-being coordinator in care homes. The different reviewers' backgrounds allowed the resources to be analysed from different angles ensuring PAMI-UK consisted of the required music therapy skills, whilst being accessible and appropriate for UK care homes. The two reviewers discussed their findings and determined required adaptations. Due to the Danish delays between December 2020 and March 2021, PAMI-UK required the UK team to incorporate some of their own ideas, while waiting for the updated PAMI-DK. This resulted in additional work compared to the initial plan to simply translate and culturally adapt the Danish intervention. Although the UK team incorporated their own ideas, they ensured they remained true to the PAMI principles and theory. The team reviewed the PAMI-DK resources again to determine which elements were essential to include in PAMI-UK to ensure that the adapted intervention kept the skills and principles of PAMI-DK.

#### 3.2.6 Development

The researcher reviewed other dementia psychosocial intervention manuals, including CHORD (McDermott, Unpublished), CST: Making a Difference (Spector et al., 2006), and Music Remembers Me (Beilharz, 2017), to gain insight into different elements, layouts, and purposes, which were considered when designing and developing the PAMI-UK manual.

A PowerPoint webinar was created to complement the manual to be used during the initial training session. A webinar was selected as the form of training delivery as it accommodated the restrictions on the researchers attending care homes during COVID-19. The webinar expands on the manual, explaining areas where staff may need more clarity, it was created to be interactive and consisted of a range of videos and visuals to engage staff and provide insight into the use of music in dementia care.

The primary researcher test ran the first draft of PAMI-UK with two music therapists from the UK PAMI team to ensure that the tool provided staff with the appropriate music skills. Additionally, the webinar was trialled to ensure the layout was suitable for Microsoft Teams (Microsoft Corporation) and that all links worked. During the session the reflective session facilitator was trained in the PAMI-UK elements. The feedback from the music therapists aided the final adaptations to the PAMI-UK version 1 prior to the first study. The PAMI-UK version 1 was sent to the Danish team for a final time for reviewing to ensure that the adaptations remained in line with the original PAMI-DK.

### 3.2.7 Revisions

During the manual field-testing and evaluation studies, feedback was collected from staff on the manual's appropriateness, usability, and readability to ensure the training was fit for purpose and audience. The feedback collected assisted in making further adaptations to the PAMI-UK training tool.

### 3.3 Results

### 3.3.1 Expert Consultations

The effects of the pandemic on care homes resulted in limited care staff consultations; however, the information that was collected aided the development of PAMI-UK and studies. Seven care staff, who held a role at their care home as either an activity coordinator, nurse, or kitchen porter, shared their experience. Staff are referred to by their job title and consultation number. For example, AC1 is activity coordinator 1. Care staff provided guidance on current music interventions in care homes and advised on the appropriateness and implantability of different intervention elements.

### 3.3.1.1 Heterogeneity in Care Homes Practices

There was an inconsistency in the standards and availability of activities and interactions provided across the UK care homes where the staff members worked. Some individuals spoke positively of their care home's current practices, while others felt improvements were needed. As activity coordinators may be the most familiar with psychosocial intervention and music, it was suggested the researchers connected with these individuals to initially introduce the study. It was felt that these staff members may be more enthusiastic about the tool owing to prior knowledge and experience. Activity coordinators could then introduce the intervention to the rest of the staff and their already developed rapport could improve carers enthusiasm and commitment. The activity coordinators involved were highly positive about the prospect of incorporating a music intervention into routines. However, they felt their area of work was underappreciated by management and carers, making involving other staff in psychosocial activities challenging.

"I have worked in activities for over 10 years, and it has always been a battle to be appreciated by management and carers, but not by the residents."- AC1 Nevertheless, individuals believed that any psychosocial intervention needed to be a complete care home approach involving all staff members.

Not all care homes had such a divide between activity staff and carers; some individuals reported that all staff were expected to complete training with the activity coordinators during induction to enable them to incorporate psychosocial interventions into their routine.

"I have always struggled with staff but now my manager expects the carers housekeeper, kitchen to spend an hour or two with me as part of induction. This has worked and we now have a great team. It's still not 100 percent as some people just don't sit well with activities but it's a lot better." AC2

Similarly to the activities, the number of resident-staff interactions varied between care homes. Some people reported that all staff engaged in meaningful interactions that were not task orientated. Individuals reported staff carving out time in their schedule when residents required 1:1s. These individuals spoke positively about staff spending time with residents to hear their life stories. On the other hand, other individuals felt that their care homes lacked meaningful interactions. The primary reason for the lack of meaningful interactions was time pressures placed on carers whilst understaffed. Residents who were unable to initiate interactions seemed to be most deprived of social contact.

### 3.3.1.2 Care Home Music Activities

When asked to comment on current music activities offered at their care home, many made a distinction between activities offered pre compared to during COVID-19 lockdowns. Prior to lockdown, many care homes provided a range of activities, including weekly choirs, music therapy, musicians visiting, intergenerational music sessions with local schools and nurseries, and singing classes. One individual mentioned staff-led music activities which consisted of personal playlists and background music listening using Amazon Alexa (Amazon.com Inc.) and CD players.

## 3.3.1.3 Appropriateness of Activities and Music

When discussing the appropriateness of available activities one individual felt that they were sometimes inappropriate, therefore additional training is required to provide knowledge and skills on suitability of activities.

"At times the activities are not appropriate for example bingo! There is definitely a need for activities staff to gain education and skills to enable more appropriate activities." N1

Additionally, one individual specifically discussed the need for greater awareness of the appropriateness of music genres played in care homes. The individual reflected on their own care home, which plays music from the 1990s. Although care staff engage through singing, residents have no connection or awareness of the songs. Alternatively, they also recounted care homes where only WW2 songs were played, which residents did not enjoy. Once again, this was not the case in all care homes. One staff member's care home played a selection of music from the '70s and '80s, allowing their residents to reminisce about positive memories associated with the songs.

## 3.3.1.4 Stakeholders' Priorities

Some individuals felt that care home owners were unaware of the importance of activities, and therefore, ranked them as low priority. One individual referred to the owner just *'wishing to tick boxes'*.

"I have had to raise all the monies spent on activities via fundraising as welloff owners do not want to pay for activities as they only want to tick boxes in some cases and do not fully understand the importance of activities and the difference a full and diverse program is to the wellbeing of the wonderful residents" AC1

Some individuals recognised their managers' eagerness to engage with interventions that benefit residents.

# "Management are completely supportive about activities and will always get on board with ideas and share their own" AC3

However, others suggested that management can feel challenged when new interventions are proposed. Managements are required to ensure care homes are running to a high standard to enable the home to pass inspections. As a result, some individuals felt management only emphasised activities when CQC inspections were due. One individual felt that managers run homes as businesses, and therefore, their priorities entail how decisions affect the business.

It was advised that to gain staff's and management's support and engagement, both had to believe in the intervention and be aware of the benefits. From previous experience, one activity coordinator commented on the need for staff to become emotionally invested in the intervention, which can be achieved when staff experience positive moments with residents.

It was believed that PAMI would require a complete mindset change for many care staff. When new interventions are introduced, care staff can feel threatened, and could interpret the new interventions as criticism of their current work.

## 3.3.1.5 Barriers and Facilitators

The primary barriers to implementation were staff time pressures and confidence in singing. Many felt that for carers the demands of attending to residents' physical health and safety resulted in little available time for social interactions and activities, therefore the intervention need to consider this during development.

"I hate to say it, but no carers do not have meaningful interactions, in my opinion. Again, the carers are too busy as they are usually understaffed, so if the resident doesn't get involved, they tend to be left to one side." -AC5

A section in the manual providing advice on singing was suggested to improve staff's confidence in using music.

Staff were asked about the practicality and appropriateness of different training elements. Group sessions was suggested as the most effective training format because completing the study together would make it less daunting. Additionally, person-led interactive group sessions would allow for discussions, with staff sharing their experiences. Training should also be provided on multiple days to accommodate different schedules. It was felt that all staff regardless of job role should gain experience in providing meaningful interactions to residents. One individual, a kitchen porter, described singing while working, which benefited residents despite her not having direct contact with them.

"I used to sing along to the songs when they were playing and doing my jobs as the residents really enjoyed listening to people sing" KP1

A paper manual was suggested by staff members as the best manual format, especially for those who experience learning difficulties owing to its ease of access. However, some suggested that offering a digital and paper manual ensures that the format is suitable for different learning styles. The use of pictures and colour was also suggested to engage and motivate staff, which could also assist with different learning styles. Other elements suggested to improve implementation were providing regular reviews, ensuring consistency with documentation and facilitators providing advice on documentation.

## 3.3.2 The Needs of a UK PAMI

Based on the seven expert consultations, the researchers' clinical experience and consultations with the Danish team, the team agreed that the current PAMI-DK was not current culturally appropriate for UK care homes and staff, initially due to the differences in the care cultures between the two countries such as care staff's education levels and then due to the COVID-19 pandemic. Figure 3.5 presents a diagram highlighting the initial thoughts on the needs of PAMI-UK, which the researcher continued to refer to through the development process to ensure the manual aligned with care home's needs.

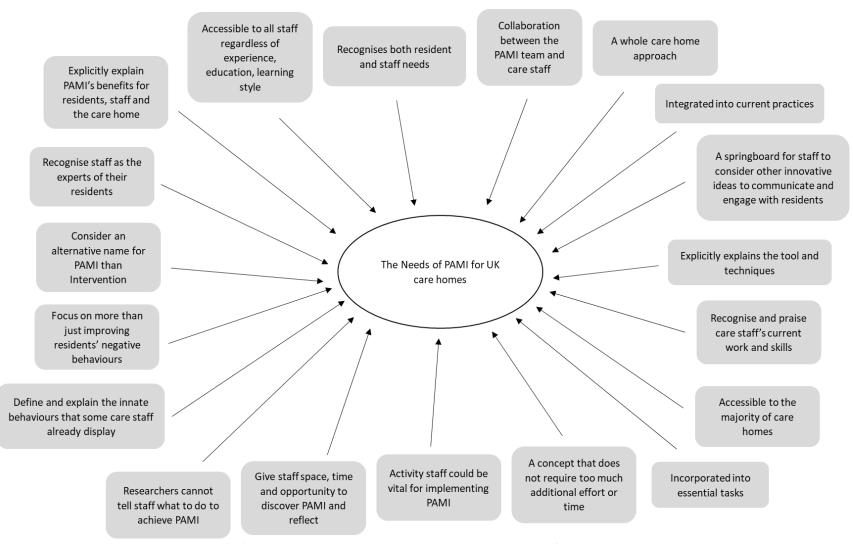


Figure 3.5 A diagram displaying the researchers' initial thoughts on the need and elements required from PAMI

PAMI-UK needs to accommodate a range of care staff who have different experiences, attributes, and learning styles. Therefore, the manual needed flexibility and adaptability to allow all care staff an equal opportunity to participate sufficiently in the PAMI-UK training. The manual needed to allow staff already displaying signs of attunement the opportunity to gain confidence, learn the terminology, and to explore and enhance their current skills and practices. At the same time, PAMI-UK needs to support and guide staff who exclusively focus on residents' physical health and safety and are unaware of attunement and musical interactions. While needing flexibility to be guided by staff's expertise and experience, PAMI-UK required more concrete guidance than provided in PAMI-DK. The manual should provide enough detail on the PAMI-UK skills that staff can return to it after the training and gain enough understanding to continue implementing them.

The researchers aimed to make PAMI-UK an accessible tool for care homes. Therefore, the researchers aimed to create an intervention that would work alongside current practices and routines. The PAMI concept is designed to be integrated into current practices, with staff using the skills to meet residents' psychological, social, and emotional needs while completing essential tasks that attend to physical needs. When PAMI-UK is used regularly, staff should use the skills spontaneously and naturally without thought or prior planning.

## 3.3.3 PAMI-UK Manual Elements

The manual begins by explaining the purpose of the training and how PAMI-UK works, including explaining the colour coding system. The PAMI-UK principles and aims are also outlined in the manual's introduction. The introduction ends with the team recognising staff's current talents, work, and attributes. The next section explores the evidence-based theory behind the manual including communication in dementia care and music. Information highlighting the importance of non-verbal communication and an opportunity to reflect on staff current techniques was included to ensure all staff have a good understanding of communication in dementia care before introducing musical interactions. The music section initially explores the importance of music for individuals before discussing music's benefits, particularly in care homes. This section helps staff realise that the reasons they enjoy music are similar to why music is important to individuals with dementia. The PAMI-UK section of the manual is split into four elements – The Voice, Framing, Balancing and Connecting. (Table 3.2)

Throughout the manual, reflective activities encourage staff to reflect on their current practice and consider how skills can be incorporated into routines. As the researchers could not enter care homes to demonstrate the skills, vignettes were included throughout the manual, providing examples of using the skills in practice. The final section of the manual provides practical tips, including information on successful communication, choosing appropriate listening devices, considering age, culture and religion, tips for becoming comfortable with using music, and examples of songs. (Appendices 3 & 4 present the manual content)

PAMI-UK Component	Aims
The Voice	<ul> <li>To increase staff's awareness of their current voice by exploring the vocal parameters: tone, pitch, tempo</li> <li>Once aware of their voice staff can learn to alter it during interactions.</li> <li>To make staff comfortable using their voice musically during work</li> </ul>
Framing	<ul> <li>To explore assessing the care home sound environment</li> <li>Learn to use PAMI-UK skills to create security and predictability</li> <li>To explore using music as a cue to orientate residents to a time, task, or event</li> </ul>
Balancing	<ul> <li>To enable staff to recognise resident's arousal states</li> <li>To explore regulating residents emotional and arousal states through appropriate music, and vocal parameters</li> <li>To enable staff to recognise their own arousal state during work</li> <li>Staff learn to centre themselves to balance arousal</li> </ul>
Connecting	<ul> <li>To explore using meaningful music during interactions to connect with residents</li> <li>To discover the skills validation, attunement and holding</li> <li>To explore person-centred interactions</li> <li>To explore and produce a PAMI-UK music plan for residents to tailor the intervention to the resident</li> </ul>

Table 3.2 A Table presenting the four PAMI-UK elements and the aim of each component

### 3.3.4 Adaptation

When reviewing PAMI-DK, the reviewers highlighted multiple areas that required adaptation to ensure the appropriateness for UK care homes. The first PAMI-DK draft was difficult to follow due to the manual consisting of mainly key words and bullet points. The majority of the information that ensured sufficient comprehension was provided in the training session and through discussions. Not only did this make it difficult for the UK researcher to understand the PAMI training sufficiently to create PAMI-UK. But they felt that the manual layout was challenging for staff to return to and use as guidance. When the UK researchers received the updated PAMI-DK in April 2021, the Danish team had made significant changes to the training and manual, which provided the UK team with a better understanding of the PAMI skills and components that could be included in the UK manual. The additional resources allowed the team to create a coherent PAMI-UK version 1.

## 3.3.4.1 Differences Between Danish and UK Manual

The adaptation led to many differences between the Danish and English manuals to ensure the adapted manual was culturally appropriate for UK care homes (Table 3.3).

Element	PAMI-DK	PAMI-UK
Intervention resources	<ul> <li>Theory book</li> <li>Practical staff workbook</li> <li>Music therapist training book</li> <li>Workshop PowerPoint</li> </ul>	<ul> <li>Theory and exercises training manual</li> <li>Webinar PowerPoint</li> </ul>
Facilitator	<ul> <li>PAMI-DK team trains music therapists who then trains care staff in care homes</li> </ul>	<ul> <li>PAMI-UK team trains care staff in care homes</li> </ul>
Training format	In-person	online
PAMI core elements	<ul> <li>Ramme (Framing in Danish)</li> <li>Regulering (Regulation in Danish)</li> <li>Relation (Relation in Danish)</li> </ul>	<ul><li>Framing</li><li>Balancing</li><li>Connecting</li></ul>
Course layout	<ul> <li>4 modules</li> <li>Theory and exercise session</li> <li>Practical hands-on training individually and in groups</li> </ul>	<ul> <li>4 modules</li> <li>Interactive theory webinar</li> <li>Reflective sessions</li> </ul>
Training length	<ul> <li>16 hours over 10 weeks</li> <li>8 hours of theory</li> <li>4 hours of individual practical training</li> <li>4 hours of group practical training</li> </ul>	<ul> <li>3-hour interactive Webinar</li> <li>Fortnightly 40 minutes reflective sessions</li> </ul>
Wording	<ul> <li>Some of the wording did not translate exactly or had different connotations</li> <li>Svag (Weak in Danish)</li> <li>Spinkel (Flimsy in Danish)</li> </ul>	<ul> <li>Weak changed to soft</li> <li>Flimsy changed to delicate</li> </ul>
Songs	<ul> <li>Uses Danish well-known songs and folk songs</li> </ul>	<ul> <li>Uses English well known songs from 1921- 1999</li> <li>Such as These Boots are made for Walking, Moon River, Wonderful World</li> </ul>

Table 3.3 The table highlights the differences l	between the Danish PAMI and English PAMI
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#### 3.3.4.1.1 PAMI Training Delivery

One of the most significant differences between the two interventions was the training delivery. Initially, both PAMI-DK and PAMI-UK would have been delivered inperson, with the facilitators regularly attending care homes to observe the skills and interactions in practice. However, in April 2020, it was decided to move PAMI-UK to an online training tool to ensure that the research and intervention could continue during the COVID-19 pandemic. (3.4.1 & Chapter 7 provides in-depth insight into COVID-19's impact on PAMI-UK development). Converting to an online tool with an accompanying paper manual led to necessary changes during the development stage. At this stage, the researchers were unaware whether the concept of attuned interactions could be conveyed successfully via a conference call where some interaction and connecting elements may be lost. More information was provided in the manual to improve usability to accommodate the online format. In PAMI-DK, practical shadowing sessions demonstrated the staff and music therapist using the skills in practice allowing the therapist to provide guidance. This training element was not viable for the online format. However, it was felt that staff still needed a space to reflect on their practice and receive guidance from the team. Fortnightly reflective sessions were introduced as an alternative to the in-person practical sessions.

Some of reflective activities required close proximity and physical contact between staff members. Not only did the UK team feel that it may be challenging to articulate the task and oversee the activity via a conference call, but also COVID-19 guidelines meant that close proximity and contact was restricted. Additionally, as a team, it was felt UK staff may feel uncomfortable completing some of the physical contact activities, such as sitting with their backs touching to feel each other's breathing, that are well-received in Denmark due to the differences in culture. Therefore, the handson tasks were removed and replaced with alternative reflective activities.

## 3.3.4.1.2 PAMI Facilitators

Additionally, the Danish team consists of music therapy researchers who provide training to music therapist on delivering the training to enable them to deliver PAMI

training to care staff (Figure 3.6). The UK team felt that using external music therapist as PAMI facilitators was unsuitable for PAMI-UK. As mentioned in Chapter 1, the availability of music therapists and care home finances has led to music therapy being unavailable to most care homes. The UK team believed using a similar delivery format as Denmark would limit PAMI-UK to the same small selection of care homes offering music therapy. PAMI-UK aims to create an intervention that is easily accessible to a broader care home population, to ensure this the UK team directly trained care staff in the PAMI-UK skills.

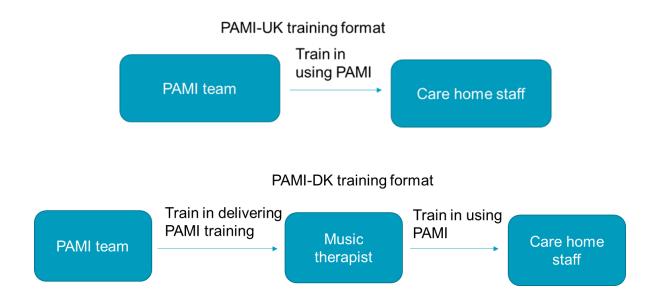


Figure 3.6 The training format for PAMI-DK and PAMI-UK

The PAMI facilitator's background was also different between the two interventions, the UK facilitator has a psychology background with experience working in a care home rather than a music therapy background. The researchers felt that having a non-music therapist facilitator could ensure that the training was suitable for staff with no prior music knowledge and highlight the ability for any individual to discover PAMI-UK. Additionally, the training facilitator was the primary researcher developing the manual and therefore was fully immersed in the skills and direction of the intervention. Although the training facilitator was a non-music therapist, a music therapist was appointed to facilitate the reflective sessions. The sessions explore terminology unfamiliar to staff, therefore, it was felt a music therapist would provide that narrative better than a non-music therapist due to them comfortably using the described skills daily. Additionally, the music therapist would have their own practical experience, that could provide greater insight for care staff. The researchers felt appointing a music therapist as the reflective session facilitator could substitute some of the components lost by being unable to offer in-person practical training.

#### 3.3.4.1.3 PAMI Training Resources

The training resources were also changed for PAMI-UK. PAMI-DK consisted of four training resources: a workshop PowerPoint, a facilitators training booklet, a staff workbook, and a theory booklet. It was agreed that having separate books for theory and practical skills could increase required staff time and effort potentially leading to them missing vital information. At the same time, the researchers recognised that staff may not have the time, intention, or motivation to read the PAMI-UK manual completely. One manual was produced to overcome the two challenges that contained both theory and practical elements. However, the theory element was drastically reduced owing to the researchers feeling that PAMI-DK was too detailed. The researchers believed that the amount of technical theory in the Danish manual could lead to staff lacking motivation or losing interest.

Coloured boxes sectioned the manual to improve useability, readability, and reduce required time and effort to locate specific elements when returning to the manual later, improving the accessibility for staff. Vital information was provided in grey coloured text boxes, which staff were strongly advised to read even if they did not wish to read any other information. A section end summary was provided for staff to use to recap. Reflective activities were outlined in yellow boxes, which staff completed during the training session to reflect on their current skills and practices. Using coloured boxes to section the activities aimed to improve the ease of finding them during the session. Finally, the practical PAMI-UK skills were presented in grey outlined boxes, and vignettes provided examples of the skills in blue outlined boxes. The speed and efficiency of locating information could be important if staff wished to refer to the manual during shifts.

#### 3.3.4.1.4 PAMI Training Length

The Danish training ran for 16 hours split into eight hours of knowledge sessions covering each of the four modules, four hours each of individual and group hands-on floor practical sessions. From the UK team's clinical experience, it was believed 16 hours would not be viable in UK care homes. Therefore, the training length needed to be significantly reduced while ensuring that essential training was not sacrificed. Through team discussions, it was decided the initial training would run for three hours, which could be completed in one session or two one and a half hour sessions. To compensate for the reduction in training time more information was included in the manual, which staff could refer to in their own time. Originally, the team planned to attend care homes regularly to monitor staff's implementation of PAMI-UK, similar to the practical floor sessions provided in PAMI-DK. However, due to the pandemic, fortnightly reflective sessions were introduced to compensate the loss in practical session.

#### 3.3.4.1.5 Differences in Language

The original manual was produced in Danish. Therefore, some changes were required when translating the manual to English due to some words not having a direct translation, words having different connotations, or being less frequently used. In Denmark, the PAMI elements are known as the three R's- *Ramme (Framing), Regulering (Regulation)* and *Relation (relation)*. The UK team felt that Regulating and Relation, despite being English words, may not be the best wording to describe the skills. Regulating was renamed Balancing, and Relation was renamed Connecting. Overall, the team felt that some of the terms and theories needed more in-depth explanation to ensure staff could engage in PAMI-UK regardless of previous experience with music, interactions, or psychosocial interventions.

#### 3.4 Discussion

The translation and adaptation stages led to both minor and significant changes to the UK manual. The changes were as a result from the staff consultations, clinical experience, and literature search. The first manual development stage was to understand the needs of UK care staff in relation to PAMI. Expert consultations were conducted with care staff, who was asked to advice on current practices, barriers to research, interventions, and practical considerations. The feedback collected from the consultations aided the researchers in developing the initial needs for PAMI-UK. These needs were considered through the translation and adaptation stages to ensure that at each stage, the manual was developed to be practical and appropriate for UK care homes.

#### 3.4.1 Considerations Required Due to COVID-19

Although the involvement of care staff was significantly reduced, consulting with them during the pandemic was beneficial as they commented on the significant care home changes and immense uncertainty resulting from COVID-19. New policies were introduced, and staff were learning how to care for their residents while preventing the spread of COVID-19, resulting in changes to routines and interactions. Staff were stretched due to increased workload and staff shortage, leaving them mentally drained with little time to participate in non-essential activities (The Queen's Nursing Institute, 2020).

Care homes may have previously experienced short-term quarantine when experiencing a disease outbreak. But care staff had not experienced the extent of quarantine and disease prevention that they experienced during the COVID-19 pandemic. As a result, there was no previous research guiding the development of care home interventions to be implementable during the challenges of COVID-19. Consulting with staff enabled the researchers to gain an understanding of the interactions occurring and components that required adaptation to ensure implementation. The feedback on currently available activities aided the researchers in adapting PAMI-UK to a format appropriate for a current and post-pandemic care

system. The information provided by staff links with the research by Alzheimer's Society (2020), Gordon et al. (2020), and Velayudhan et al. (2020). The lockdowns led to the removal of most provisions, interventions, and interactions leading to some residents going from an enriched daily schedule full of activities and interactions to experiencing a restricted daily schedule when the pandemic began, where interactions occurred with a restricted number of staff and residents. It must be remembered though that care homes in the UK vary in provided provisions, and some care homes had limited available activities and interactions pre-pandemic.

Prior to the COVID-19 pandemic, PAMI-UK aimed to integrate skills into current routines, however, the feedback from staff led to the researchers being more conscious of how skills could still be used when residents were isolating. Based on the feedback, the researchers emphasised the use of PAMI-UK during personal care, which was necessary even during isolation, to ensure that residents' psychological, social, and emotional needs are met during isolation periods (Chu et al., 2021a; Fewster, 2020).

#### 3.4.2 PAMI-UK's Aims and Needs

The first step of adapting PAMI was outlining clear aims, purposes and needs to ensure the development of an appropriate and practical tool. The first step was to understand the core aims and principles of the original PAMI to ensure that during adaptation these core ideas remained. As the development progressed, the researchers also needed to navigate the needs of the manual in relation to COVID-19. Through feedback from staff, the research team's clinical experience, and the systematic review, the team determined the required PAMI-UK aims and elements to ensure the appropriateness for UK care homes and that it targeted the intended outcomes.

The Danish team feel that PAMI aims to create a manual for a concept which is difficult to understand through written text; rather it needs to be experienced (Ridder et al., 2023). Both UK and Danish researchers felt that PAMI is not a concept

that can be taught; instead, care staff must discover it (Ridder et al., 2023). PAIM-DK targets the main aim by providing staff with music therapists' expertise through discussions and clinical shadowing. Whilst the UK researchers agreed with the Danish team, they felt that more information needed to be in writing to allow staff to continue to return to the tool after formal training ended. The addition of COVID-19 also resulted in PAMI-UK needing to alter the delivery. The clinical shadowing was altered into reflective sessions. Although this meant that staff would not be able to observe the skills in practice and gain guidance while using the skills, the team hoped the sessions would still be able to provide some support and guidance during the COVID-19 restrictions. One of the Danish team's main aims is to provide staff with the terminology to describe their interactions. PAMI-UK retained the lived experience descriptions used in the PAMI-DK. Lived experience descriptions are inspired by Van Manen's (2017) phenomenological approach to the subjective description of human experiences, which encourages staff to verbally articulate their interactions to capture the instant moment, with guidance from a music therapist, a concept they may have struggled with pre-training (Ridder et al., 2023).

Care staff can feel criticised when researchers implement new interventions in their care homes due to interpreting the change as researchers suggesting that their current practices are incorrect (Lawrence et al. 2016). Furthermore, staff can also feel unappreciated for their work, leading to further feelings of criticism and tension with the researcher when they attempt to introduce interventions (Lawrence et al., 2016; Cooke, 2018). The researchers decided to refer to PAMI-UK as a tool rather than an intervention to reduce anxiety and chances of feeling criticised. A section at the beginning of the manual was introduced to celebrate care staff's hard work and skills. PAMI-UK aims to be a collaborative training where staff are recognised as experts with their skills and talent incorporated into the intervention. Overall, the training should provide staff with space, time, and opportunities to reflect on their practices and discover PAMI-UK rather than being taught PAMI-UK. The researchers hoped that these changes would make care staff feel less criticised and, therefore, more open to exploring the PAMI-UK skills.

Many psychosocial interventions focus exclusively on improving 'negative behaviours'. In contrast, PAMI recognises 'negative behaviours' as potential communication of unmet needs. PAMI's main aim is to enable care staff and residents to develop attuned interactions, which can improve more than just residents' behaviour, including quality of life, mood, staff burden, and competence. Additionally, many psychosocial interventions focus exclusively on improving the residents' behaviours (Lawrence et al., 2021.; Backhouse et al., 2016; Lievesley et al., 2011); PAMI recognises the impact of staff behaviours impact on residents, as well as attending to care staff needs. The training provides skills for staff to recognise and alter their behaviour to align with residents' needs, whilst also providing coping mechanisms and skills to improve staff burnout, stress, wellbeing, and mood.

#### 3.4.3 Stakeholder Priorities

Four stakeholders need to be considered when implementing interventions into care homes, each having different priorities. During the staff consultations many, especially activity coordinators, felt that managers and care home owners are unaware or uninterested in the importance of providing activities aimed at improving residents' well-being. From the feedback received, the researchers aimed to highlight to managers the potential benefits for their staff and residents and the running of the care home, including improving task efficiency. If it is highlighted how PAMI-UK aligns with the stakeholders' priorities, there is an increased likelihood of managers and staff engaging with the intervention.

Staff feeling undervalued and underappreciated by managers, relatives, and the public is not exclusive to the staff in the consultation (Lawrence et al., 2016; Kadri et al., 2018). The feedback from individuals feeling underappreciated led to the manual recognising and praising the work and skills care staff display. The word intervention may lead to staff feeling criticised; instead, PAMI-UK is referred to as a training tool when discussed with care homes and staff.

Some staff already display skills similar to PAMI-UK without requiring training. However, other care staff, who have a "get things done" mindset may be good at ensuring residents are well cared for and safe. But focuses exclusively on physical care without developing meaningful social relationships with residents (Wilson & Davis, 2009). Staff in both the expert consultations and previous research (Lawrence et al., 2016) have highlighted that some carers do not engage in psychosocial interventions due to holding the attitude that their job is only to clean and feed residents. For staff with a 'get things done' mindset, PAMI-UK would be a complete mindset change, especially for those who may have been working in dementia care for a significant time.

Rather than tell staff how to "complete" PAMI-UK, the training tool aims to provide the space and opportunity for staff to explore PAMI-UK and build on their current skills and routines without expectations or judgement from the facilitators. Motivating care staff can be challenging. However, the staff consultations suggested that highlighting the personal side of care by personalising it to the staff's care home could increase care staff's motivation and engagement.

#### 3.4.4 PAMI Format

The flexibility of PAMI is key to ensure that the intervention can be tailored to each resident to promote person-centred care. The work by Anderson-Ingstrup (2020) discussed the appropriate format for the PAMI manual suggesting a framework that was adequately flexible to tailor the intervention to each individual whilst maintaining sufficient information to enable staff to implement the skills successfully. Whilst the UK team understood and agreed with the Danish ethos of exploration and flexibility, it was felt it would not work to the same extent in the UK. It was felt that PAMI-UK needed to explicitly explain the techniques to ensure the implementation of high-quality music skills. More concrete information was required in the manual to ensure that UK care staff understood the training sufficiently and could return to the documents outside of the training and it remain coherent. PAMI-UK had a non-music therapist as the lead training facilitator. Therefore, PAMI-UK

training required more concrete content developed before the training to ensure that the training facilitator could provide accurate and high-quality skills to staff. From their clinical experience, the researchers felt this format would be more appropriate for UK care staff, who may lack confidence in the tool and skills, ensuring a high-quality version of PAMI-UK is likely to continue after the training ends.

The staff consultations and literature search highlighted the inconsistency in standards across care homes. Therefore, to make PAMI-UK accessible to a wider population of care homes, the intervention needed to be developed in a way to accommodate different levels of training depending on the staff baseline knowledge, education, and attitudes. The Danish and UK teams felt some staff are already attuned to their residents, with many using musical interactions (Ridder et al., 2023). However, these behaviours may be performed subconsciously, impeded by the current care system, or staff lack the appropriate terminology to describe the interactions. For these staff, PAMI-UK aims to define and expand on staff attributed by providing a space to reflect on and explore them. At the same time, some care staff focus exclusively on residents' physical health and safety needs. PAMI-UK needed to introduce the skills and highlight the essentialness of attending to residents' psychological, social, and emotional needs for these staff members. During the PAMI-UK training, the facilitator needs to adapt the training to reflect the staff's experience and knowledge.

The development of the manual highlighted the need for PAMI-UK to potentially be a care-home-wide intervention. Integrated PAMI-UK as a whole care home approach with all staff trained could ensure consistency regardless of shifts and create security and predictability, two vital elements in PAMI. PAMI-UK has the potential to change the care home culture experienced in UK care homes. Although this is beyond the scope of the current project, the researchers aimed to develop the training tool with this in mind to ensure that PAMI-UK could be upscaled in the future.

#### 3.4.5 Manual and Study Elements

Care homes can be challenging environments to conduct research in because they are the home and workplace for many, making some study designs unrealistic (Luff, 2015). Feedback on the study design and manual elements ensured that the PAMI-UK studies would be practical for care homes and limit additional burdens for staff. Feedback from staff enabled the researchers to develop a tool that would be accessible regardless of previous experience or education.

Due to COVID-19, the training tool and study were required to be completed online; this led to several challenges that the researchers had not previously considered when developing an in-person training. Some individuals preferred online manuals; however, there was concern around accessibility to multiple devices during training. Many care homes had outdated technology systems in place with limited access to computers and tablets and poor Wi-Fi connection making them unprepared for the move to remote and technology-based care during the pandemic (Chu et al. 2021b; Care Quality Commission, 2020; Khowaja et al., 2023). The accessibility of technology for training in UK care homes was a concern of the researchers. As a result, feedback was collected from staff on their care home's ability to access computers and WI-FI to complete online training. Many care homes had seen an increase in technology usage owing to the pandemic, with video conferencing platforms not only being used for training but increasingly used with residents to connect with families (Chu et al. 2021b; Care Quality Commission, 2020). Interactive elements were suggested to improve engagement and interest and could compensate for the personal element lost with online training. Staff would be able to discuss the skills and current practices with colleagues to explore how PAMI-UK could be specifically incorporated in their care home. A systematic review by Nolan et al. (2008) highlighted that many of the authors in the review promoted interactive training with opportunities for staff to reflect on personal experience as a valuable element of training.

Although most staff receive training in communication, there is no mandatory accredited training for communication (Smith et al., 2019). Therefore, a

communication section was included as a reminder to staff, and to guide those who may lack confidence or experience in successful communication in dementia care. The section can be explored by staff who may not have other opportunities to gain in-depth training in that area. At the same time, it can be skipped by staff who feel they have competent dementia communication skills. It can be challenging to engage in attuned musical interactions if staff lack the understanding and skills of communication. Including knowledge on communicating ensures that all staff have the foundations before moving on to the PAMI-UK skills.

#### 3.4.6 Practical Considerations

When implementing music interventions into care homes practical considerations are required to ensure successful implementation. During the manual development process, it was highlighted that the music genres played in care homes may be inappropriate, which has the potential to lead to ineffective music interventions (Hutson et al., 2015; Paolantonio, 2021). To encourage staff to use more appropriate music, a music catalogue was collated with input from generations who may currently require care home placement (aged 50-95), to suggest appropriate music to staff. Although staff are encouraged to discover their resident's preferred music to make the interactions person-centred. Previous work (Beilharz, 2017) and clinical experience suggests that music interventions may be unsuccessfully implemented due to overlooked practical elements, including appropriate listening devices and religious and cultural considerations, therefore these elements have been explored in the manual providing staff with the required knowledge prior to implementing PAMI-UK. The researchers hoped that by adding a practical consideration section into the manual it would make staff feel more comfortable incorporating music into their routines resulting in increased likelihood of long-term successful implementation and reduce barriers highlighted in previous research.

# 3.4.7 Implementation

The significant barriers to implementation highlighted in the staff consultation and literature search were available time and staff confidence in singing (Stanyon et al.,

2016; Windle et al., 2019; Savundranayagam, 2014; Götell et al., 2009). Chapter 1 highlighted similar barriers making many psychosocial interventions inaccessible due to finances, staffing, available time, or required equipment. PAMI-UK aims to overcome these, making the tool accessible to a broader care home population. Although the original PAMI aimed to reduce the barrier of time pressures, the feedback led to the researchers concentrating more on the burden and commitment required for the PAMI-UK tool and studies. The researcher developed both the studies and tool to minimise additional burden to staff's current pressures. By incorporating skills into current routines and essential tasks the tool requires little additional time or effort to reduce the risk of increased staff stress or burden and improve the long-term implementation success. With the skills learnt, the researchers hoped staff could experience reduced burden and time pressures through improvements in task efficiency and residents' arousal levels.

#### 3.4.8 Own Clinical Experience

The primary researcher and PI have experience working in care homes that aided the PAMI-UK development as it ensured that throughout the development process the intervention was developed to be practical for care home settings. However, the researchers were conscious that their clinical experience may cause bias during the development stage. The team were aware that UK care homes vary greatly and that their clinical experience was limited to the care homes they had worked in. The staff consultations aimed to ensure that their personal experience did not limit the team and that PAMI-UK was appropriate for a wide range of UK care homes. Additionally, the primary researcher completed a reflective diary throughout the project.

#### 3.4.9 Next Stages in the Adaptation Framework

During the manual development stage, phase one of the cultural adaptation frameworks was achieved. The researchers generated knowledge and collaborated with stakeholders through consultations with care staff and the Danish PAMI team, conducted a systematic review and considered their own clinical experience to determine the required cultural adaptations. Phase two of the cultural adaptation frameworks was also achieved as the information generated in phase one was used

to develop PAMI-UK version 1. The next phase of the framework is to review the adapted intervention with stakeholders and make amendments based on the feedback. To ensure that PAMI-UK is appropriate for UK care homes a manual field-testing study was conducted to review the acceptability, readability, and usability. The results from the study will aid further adaptations to produce PAMI-UK version 2.

#### 3.4.10 Limitations and Future Research

Due to the COVID-19 pandemic, the involvement of stakeholders in the development of the PAMI-UK intervention was significantly reduced and limited. The researchers were only able to have discussions with care staff, and as they were identified through the researcher's professional social media network, most individuals were activity coordinators. While the activity coordinators were able to provide important insight into the incorporation of psychosocial interventions into care homes, the lack of representatives from other care home positions potentially means that there was a lack of insight into how to design the intervention best to work for roles such as carers who have less time and flexibility. Additionally, speaking to managers would have enabled the researchers to gain a greater insight into designing PAMI-UK to target managers' and owners' priorities. Discussions with managers would have also highlighted psychosocial interventions' practical and business considerations, such as potential costs and staff scheduling. As the PAMI-UK manual resources continue to be developed in the future, consideration should be given to including managers, care staff, residents, and family members of residents in the development process now that the COVID-19 restrictions have been removed.

#### 3.4.11 Conclusion

The PAMI-DK manual was translated from Danish into English before being adapted to become more culturally appropriate for UK care homes. From the expert consultations it was highlighted that the current practises in care homes varied and therefore, PAMI-UK required flexibility to accommodate differences in staff experience, attributes, and knowledge, to ensure equal opportunities to discover PAMI-UK. The most significant changes required from PAMI-DK to PAMI-UK were the

training delivery and length. The PAMI-UK team decided to directly train care staff compared to PAMI-DK which trains music therapists in delivering the PAMI training to care staff. The training length was significantly reduced to ensure that it could fit into care homes current routines which generally have little time to allow staff to attend training. Some changes were required part way through the development process which the team had not anticipated. The PAMI-DK training had been developed pre-pandemic when in-person training was possible. Whereas the PAMI-UK was developed during the COVID-19 pandemic and therefore had to be converted into an online training tool. As a result of converting to an online tool, elements needed to be adapted to ensure the tool was appropriate for online delivery and abided by the COVID-19 guidelines. Despite the need for significant changes, PAMI-UK has aimed to keep the core principles, including person-centred, experience-led and the ideology that PAMI is a concept that cannot be taught, instead staff must discover it through reflection and exploratory practices.

# 4. Manual Field-testing Study and Evaluation Study Methodology

This chapter has been adapted for an article: Waters, B., Orrell, M., & McDermott, O. (2022). The development of a UK culturally adapted version of the Person Attuned Musical Interaction (PAMI) manual: protocol for a two-phase mixed method study. *JMIR Research Protocols*. 21(1). https://doi.org/10.2196/43408

# 4.1 Introduction

To test and evaluate the adapted manual two studies were conducted. A manual field-testing study to investigate the manual's feasibility, usability, and readability to ensure that the manual is suitable for the intended audience of care staff and the intended setting of UK care homes. The data collected in the first study aided any revisions to the manual to create PAMI-UK version 2 and aided revisions to the study design for the manual evaluation study.

The manual evaluation study aimed to collect preliminary data on PAMI-UK's impact on residents and staff. The study also collected further data on the manual's feasibility, usability, and readability to ensure that PAMI-UK version 2 is suitable for use. Both studies collected data to investigate the practical implication of PAMI-UK in care homes and staff and residents' experience using the tool. Some of the methodology for the two studies was the same and therefore has been presented in this chapter. However, some methodology is specific to one of the two studies; these methodology elements can be found in Chapter 5 for the manual field-testing study and Chapter 6 for the manual evaluation study.

# 4.2 Methods

# 4.2.1 Study Overview

Two studies were conducted to investigate the aims, which follow the stages of the MRC and cultural adaptation frameworks. Initially a field-testing qualitative development study reviewed the culturally adapted manual (version 1) with its intended stakeholders (care staff and residents with dementia) to ensure appropriateness. Data was collected on the factors influencing implementation and stakeholders' (care staff and residents) experience with PAMI-UK. The data collected in the first study aided adaptations to the manual and study design in preparation for the second study.

The second study was mixed methods that continued to review the culturally adapted manual (version 2) with its intended stakeholders. Additionally, the study collected preliminary data on the impact of PAMI-UK on staff and residents to begin investigating the Feasibility and piloting stage of the MRC guidelines. The data collected in the second study aided further revisions to the manual (version 3) and will aid the development of future studies to continue to explore the feasibility and piloting stage. Figure 4.1 displays the study overview.

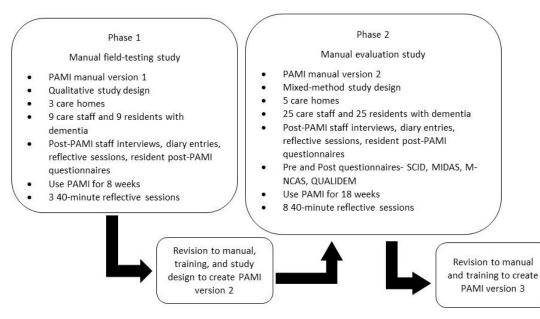


Figure 4.1 Study overview consisting of two phases and two revisions stages. The study overview was developed based on the MRC guidelines for complex interventions and culturally adapting intervention frameworks

#### 4.2.2 Ethics

The project received ethical approval from the London - Harrow Research Ethics Committee on 29<sup>th</sup> of June 2021 (REC reference-21/LO/0283) (See Appendix 6 & 7). Amendments to the second study were approved by the London- Harrow Research Ethics Committee on the 22<sup>nd</sup> of March 2022 (See Appendix 8).

#### 4.2.3 NHS Trust Collaboration

A collaboration with the Lincolnshire Partnership NHS Foundation Trust was created early in the manual development process, which assisted with the running of the studies in care homes. As part of the collaboration, PAMI-UK was advertised through the Trust's Enabling Research in Care Homes (ENRICH) organisation. ENRICH is a national organisation developed by the National Institute for Health Research (NIHR) to support care homes staff, residents, families, and researchers to implement research into care homes more smoothly, accessibly, and effectively. The primary researcher presented PAMI-UK at several monthly ENRICH forum meetings, which allowed the researchers to advertise and recruit care homes involved in the scheme.

The Lincolnshire Trust developed a pilot In-Reach scheme in 2020 to improve the accessibility of care home research within Lincolnshire, with PAMI-UK being one of the first projects to be involved. Involvement in the scheme led to an In-Reach Practitioner (RF) joining the team. RF liaised between the researchers and care homes with whom they already had a rapport. This rapport meant that RF was already aware of potentially suitable care homes, reducing the time needed for introductions, provided a recognisable face, thus reducing anxiety among potential participants. The practitioner supported the researchers in setting up and running the study by introducing the study to care homes, recruiting participants, distributing documents, assessing capacity, obtaining consent, introducing care homes and the researchers, collecting documents and being an in-person contact for the research team. When designing the study, the researchers were uncertain about the possibility of them attending the care homes owing to COVID-19, however the In-

Reach Practitioner is an NHS role, allowing them to continue attending the care homes throughout the studies. Having an in-person contact provided additional support for both the researchers and participants allowing issues and the setting up and running of the study to be managed more quickly and efficiently. The care homes involved in the In-Reach pilot scheme belonged to ENRICH and were invited to join the scheme.

#### 4.2.4 Recruitment

Care homes were recruited first through the In-Reach scheme or advertisements through the Lincolnshire ENRICH. Once care homes were recruited, two participant types were recruited: care staff and residents with dementia. The researchers first contacted care home managers, who then introduced the team to interested individuals. A management introductory letter introduced the study and provided the potential benefits for care staff, residents, and care home. The letter also informed managers of the required time commitment from themselves, staff, and residents, to ensure that their care home could commit the required time. The welcome pack also contained introductory letters for care staff, residents, and residents' families, which managers were asked to distribute.

Care staff were recruited first before residents to enable staff to communicate the study to residents. As the researchers could not access residents' care plans, therefore, the researchers required care staff to distribute the information sheets to eligible individuals. Interested individuals expressed their participation by contacting the researchers using the provided contact details or informing the In-Reach Practitioner when she attended the care home. Interested individuals were provided with an information sheet and consent form to consider their participation.

RF attended the care homes during the recruitment period to discuss the study with individuals and answer questions. The researchers originally aimed to recruit participants in-person to develop a rapport between the care homes and researchers; however, due to COVID-19 guidelines, correspondence, outside of the

In-Reach Practitioner, were completed via post and email. Once care staff and residents were recruited, residents were paired with the participating care staff they have the most direct contact with daily.

#### 4.2.5 Informed Consent

Written informed consent was collected from all participants at the start. There were different information sheets for staff and residents. A dementia-friendly version of the resident information sheet was created for residents who may struggle to comprehend the formal participation sheet (Appendix 9, 10, 11). The dementia-friendly information sheet was shorter, only providing the essential information and was writing in simpler language, with pictures accompanying the text to improve comprehension. Interested participants were provided with the information sheet and consent form and provided a week to consider their participation. During this time, potential participants could contact the researchers to discuss questions or concerns.

If individuals wished to participate, a consent meeting with RF was organised to review the documents, ask questions, and sign the consent form. The consent meeting could be completed either in-person at the participating care home or online via Microsoft teams (Microsoft Corp). Once the consent forms were signed, one copy was given to the participant, and the researchers kept a copy. A third copy was kept in the resident's care file when resident participants consented. Consent is an ongoing process; therefore, the researchers continued to regularly check participants consent. Some residents may have been unable to consent verbally; therefore, the researchers worked with the care homes to determine the most appropriate form of communication for each resident.

#### 4.2.5.1 Researching with Adults Who Lack Capacity

The studies involved participants who lacked capacity owing to their dementia diagnosis. The Mental Capacity Act 2005 (Department of Health, 2005) was followed to determine participants' capacity to consent. The researchers had all previously worked in care homes, where their role required the understanding in residents

lacking capacity and have completed training in informed consent with adults who lack capacity. Individuals were deemed to lack capacity if they could not make a particular decision themselves. The Mental Capacity Act (2005) states that a person is unable to make their own decisions if they cannot do at least one of the following four things:

- Understand the information given to them
- Retain the information long enough to be able to make a decision
- Weigh up the information available to make the decision
- Communicate their decision through a form of communication accessible to the individual

With assistance from the care homes, RF assessed the resident's capacity to consent during the consent meetings. If the resident was deemed to lack the capacity to consent, RF worked with the care home to appoint a consultee. The consultee was a family member, friend, or appointed power of attorney who was not involved with the study and had the resident's best interest. Once the consultee was appointed, they received an invitation letter, consultee information form, and consultee declaration form to consider whether their relative (the term relatives is used to also refer to those whose consultee is a friend or power of attorney) would want to participate in the study (Appendix 12). The consultees were provided a week to consider their relative's wishes before a consultee meeting was organised to review the documents, asks questions, and sign the form. The consultee meeting took place either in person or online via Microsoft Teams. Staff and relatives could use the dementia-friendly information sheet to discuss with the resident their participation. For residents deemed to lack capacity to consent, assent was obtained on top of their consultee's declaration, using the most appropriate communication form, to allow residents to remain involved in the decision process when not legally able to consent. During the study, for residents unable to verbally assent, their behaviour was observed for signs of wishing to withdraw or distress. The researcher gained regular updates from the care homes on resident's behaviour due to the inability to attend themselves in-person.

Dementia is a progressive condition; therefore, there was potential for resident participants to lose capacity during the study. The researchers reviewed the resident's capacity throughout with assistance from the care homes. Consultees would have been appointed if needed, however, no residents in the two studies lost capacity during the study.

#### 4.2.6 Withdrawal

Care staff participants were reminded at the start of each reflective session that theirs and their resident's participation was voluntary, and they could withdraw at any time without providing a reason. Participants were also reminded that withdrawing would not affect the care they received as a resident or their employment as a staff member. Staff were also asked to report any PAMI-UK issues during the reflective sessions. In between sessions, participants could contact the researchers via email or telephone to report any issues or wishes to withdraw. All study activities ceased immediately if a participant withdrew, and no further data was collected. However, data already collected was used in the final analysis. As participants participated as dyads, both participants were withdrawn from the study, if one withdrew. The only exception was if only the completion of the staff interview remained, and the resident withdrew; in this case, the staff could still complete the interview, but only reported on their experience of the training. Withdrawn participants were not replaced. The researchers felt it was ethical to withdraw residents from the intervention if their staff member withdrew as they would still indirectly receive PAMI-UK interactions from other participating staff members.

#### 4.2.7 Setting

The two studies were conducted in Lincolnshire care homes caring for individuals with dementia. Different care homes participated for the two studies. The care homes could be private, voluntary, NHS, or Local Authority owned and provide either residential, nursing, or both types of care. All care homes had to meet the eligibility criteria.

# Care homes eligibility criteria

- They should have received a score of 'Needs improvements' or 'good' on their most recent CQC report
- Have adequate WI-FI for staff to attend the PAMI-UK training and reflective sessions

Care homes with a score of 'outstanding' were excluded as they already display a high quality of care. Consequently, it would have been challenging to determine the effect of PAMI-UK. Care homes with a score of 'inadequate' were excluded as they would likely need to dedicate time towards improving other areas of care and, therefore, may not be able to dedicate the time required for the study.

The In-Reach Practitioner reviewed care homes' eligibility to determine whom to introduce the study to. As all the care homes were part of the In-Reach pilot and ENRICH, the care homes in the studies may have been more proactive and aware of interventions compared to other care homes.

# 4.2.7.1 Research in Care Homes

Conducting research in care homes can be complex, as mentioned previously. The researchers all have experience working and communicating with individuals with dementia from previous jobs in care homes ensuring they had sufficient skills to support the residents in the study. The researchers were also aware that due to variations in impairments, that resident's level of participation would vary, such as some being unable to complete post-intervention questionnaires. The researcher aimed to support the resident participants to be involved as much as possible, they worked with the care homes to support each resident based on their abilities and impairments to ensure this could occur.

As a result of living in the care home, residents may not have had the means to contact the researchers. Residents could pass any information for the researchers to

the participating care staff or care home manager. However, there were concerns about residents wishing to discuss sensitive or confidential information, especially if it involved the participating care staff. As a result, interest and concern sheets were provided to each care home with sealable envelopes, which residents could use to communicate with the researchers. Dementia impairments meant that some residents may be unable to write coherently; therefore, RF attended care homes through the study for residents to communicate any issues or questions. When RF attended the care homes, she collected completed interest and concern sheets which were responded to promptly.

The researchers worked with the care homes to work around the staff and care home schedules and routines and to select convenient times for the training and reflective session. The researchers aimed to stick to the research timeline; however, they were aware that the care staff's shifts may not correspond to the researchers' timeline, and therefore, the researcher needed to be flexible.

#### 4.2.8 Online Delivery of the Study

The training, reflective session, and interviews were all completed online using a conference call platform. Microsoft Teams (Microsoft Corp) was selected because of its ease of use, it allows up to 250 individuals to join a call, it allows for screen sharing, it is not time-limited, it can record sessions and is encrypted, making it safer. The NHS Transformation Directorate Department (Formally known as NHSx) confirmed in 2020 that Microsoft Teams is safe for use in health care (NHSX, 2020; NHS Digital, 2020). A Team channel was created for each care home where the training, reflective sessions, and interview meetings were created. A Microsoft Teams information sheet was created providing information on joining Microsoft Teams channels and meetings for participants unfamiliar with the software. The guidance sheet was also provided to consultees completing their consultee advice meeting online. For ease and consistency, when the UK COVID-19 guidelines lifted, the training, reflective sessions, and interviews remained online.

#### 4.2.9 PAMI-UK Intervention Structure

The PAMI-UK intervention can be split into three components: A paper manual, the initial training session, and fortnightly reflective sessions. All staff completed the training, and all residents received the intervention.

#### 4.2.9.1 PAMI-UK Manual Format

Each staff participant received a paper copy of the PAMI-UK manual at the beginning of the study which was theirs to use throughout the study. The manual consists of theory, reflective exercises, examples, and practical skills. Staff were required to bring the manual to the initial training session as the reflective exercises are completed and discussed during the training. Coloured boxes separate the different elements guiding staff through the manual (More information on the manual in Chapter 3).

#### 4.2.9.2 PAMI-UK Training Session Format

The primary researcher (BW) facilitated the training sessions with assistance from a music therapist (BS), another team member. BS is a qualified music therapist who completed her training in the USA. She has experience working in residential old age care as a music therapist and at the time of the study was a PhD student who was completing her secondment with the PAMI-UK research team. A 3-hour group interactive webinar via Microsoft Teams was delivered at the study's beginning, which care homes could complete in one session or split into two shorter sessions. The training was organised at the convenience of the care homes and care staff. The group interactive webinar consisted of theory and interactive reflective activities (Appendix 4). The training session follows the manual layout, with staff completing the reflective exercises in the manual during the session. Different learning elements have been used, including written text, pictures, talking, interactive activities, videos, and the music therapist experience, to make the training accessible to many learning styles. During the session, staff were provided with examples for implementing the skills and theories into practice. PAMI's central ethos is person-centred, therefore, what skills and how frequent skills are used are at the staff's discretion. Staff are

instructed to use PAMI-UK regularly on each shift in relation to their resident's needs, impairments, and preferences.

# 4.2.9.3 Reflective Sessions

BS facilitated the reflective sessions with assistance from BW. The sessions were conducted once a fortnight for 40 minutes via Microsoft Teams. The session held two purposes, 1) to get staff to reflect on their practices and their experience implementing PAMI-UK and 2) to collect data on using PAMI-UK in care homes. Unlike the training, which has more structure, the reflective sessions are less formal and guided by the care staff (table 4.1). Three of the reflective session focus on one of the specific PAMI-UK elements each session to ensure that staff understood each element and had attempted to implement the skills. The sessions were an opportunity for staff to reflect on the previous fortnight which the facilitator guided using a range of prompts. The music therapist encouraged and supported staff to develop verbal lived experience descriptions to describe their interactions. A reflective session outline was developed by BS to guide which elements to discuss in each session. The outline also provided potential questions the facilitator may wish to ask to prompt discussion. (Appendix 14)

#### Table 4.1 Reflective session content layout

Manual field-testing study	Manual evaluation study
Session 1- Connecting- music plans	Session 1- Check in- getting to know PAMI-UK and your resident
Session 2- Framing- sound environment,	Session 2- Framing- sound environment,
cueing	cueing
Session 3- Balancing- the voice,	Session 3- Balancing- the voice
attunement	
	Session 4- Connecting- attunement,
	Holding, validation, reminiscence
	Session 5-9- Review and supervision

#### 4.2.10 Data Collection

Data was collected in several ways across the two studies. The qualitative data collection methods stayed the same in both studies. The qualitative data aimed to determine the manual's feasibility, appropriateness, usability, and readability for UK care staff. The qualitative data also provided insight into the practical implementation of PAMI-UK, and the care staff and residents' experience. The quantitative pre- and post-intervention questionnaires were only collected during the manual evaluation study (Information on quantitative data collection available in chapter 6).

#### 4.2.10.1 Demographic Questionnaires

Staff completed a resident and staff demographic questionnaire. Staff were encouraged to work with their resident to complete the resident questionnaire, but residents' involvement depended on their impairments and communication abilities. A dementia-friendly version of the questionnaire was created to allow residents to have more involvement without impairments hindering participation. The staff questionnaire included the questions: age, gender, nationality, length of time at the care home, length of time in dementia care, and views on music in dementia care.

The residents' questionnaire included the questions: age, gender, nationality, length of time at the care home, communication ability, and interest in music.

Participating care homes completed a care home demographic questionnaire. The care home questionnaire included the questions: care home type, resident type, number of residents in the care home, staff: resident ratio, the current availability of music and activities, and availability of Wi-Fi and technology. The question about the availability of Wi-Fi and technology was to ensure that care homes had adequate accessibility for staff to access the online training.

Staff members completed the Dementia Severity Rating Scale (DSRS) (Clarke & Ewbank, 1996) for their resident to determine dementia severity. The DSRS is an informant-based multiple-choice assessment tool, consisting of 12 items covering a range of functions impacted by dementia including: memory, language, recognition of family members, orientation to time, orientation to place, ability to make decisions, social and community activity, home activities and responsibilities, cleanliness, eating, control of urination and bowels, and ability to get from place to place. In each category, the informant is provided with a numbered list of descriptions describing the individual's level of functions. For example, the description marked as zero would indicate a normal function, whilst the highest number would indicate severe impairment. The numbers are added together, and the total determines the dementia severity. A score of 0-18 indicates normal to mild dementia, 19-36-moderate dementia, and 37-54- severe dementia. The DSRS has a high internal consistency, high concurrent validity, high test-retest, and high interrater reliability with carers rating similarly to trained clinicians and non-medical professionals (Clarke & Ewbank, 1996). The DSRS was selected due to its ease of use, ability to be completed without a researcher, and its high validity and reliability.

# 4.2.10.2 Diary Entries

The staff were asked to keep a diary, produced by the primary researcher, to document their use of PAMI-UK and thoughts (Appendix 19). A paper and pencil

method were selected over a more technology-based method to ensure all staff could complete the entries during their shift. It is suggested as one of the easiest diary methods and therefore requires little instructions at the beginning of the study (Bolger & Rafaeli, 2003).

Diaries for data collection are a flexible self-reporting tool that allows researchers to collect data on everyday situations. The current project used an event-contingent diary format where staff documented every PAMI-UK interaction during the study. Therefore, if the diary was used correctly, staff should complete at least one entry every shift (Bolger & Rafaeli, 2003; Day & Thatcher, 2009). Diaries allow participants to document their experiences regularly, therefore, increasing accuracy due to the lack of need for retrospection. Although immediate recording after the event would lead to the greatest accuracy, the researchers were aware that this might not be logical or practical in care homes. Staff were informed they could either report each interaction as they went or document all interactions that had occurred at the end of each shift. Staff were advised that the best time to complete the diary entries may be whilst completing other care documents.

Bolger & Rafaeli (2003) suggested diary entries are a valuable data collection tool to achieve three research goals 1) obtain reliable person-level information, 2) examine within-person change over time, 3) conduct a causal analysis of within-person changes and individual differences in the change. Data was collected on the time and date of interaction, interaction length, the interaction's corresponding PAMI-UK element, what the interaction entailed, the resident's reaction, PAMI-UK's impact on the interaction, and space for additional comments. The data collected aimed to provide the researchers with a greater understanding of when PAMI-UK may be used within care homes, if there was an optimal number of usages, elements of PAMI-UK most understood or used, and the impact of PAMI-UK on residents and the interaction. The data collection method aimed to allow the researchers to examine whether the use of PAMI-UK or the documentation changed over time, particularly in

relation to the reflective sessions. Finally, the diaries collected data to investigate individual differences between participants.

The use of diaries relies more on the participant than other qualitative methods as the researcher is not present for the documentation. The method relies on individuals' commitment and motivation to complete the entries (Bolger & Rafaeli, 2003). The diary entry form was kept simple and quick to complete, with each entry only taking a few minutes, to improve the completion rate. At the end of the reflective sessions, staff were reminded to continue to complete the diaries for PAMI-UK interactions experienced over the following fortnight.

Previous research (Bolger & Rafaeli, 2003) has suggested that using diary entries as a data collection method may affect participants' experience or reaction, with participants experiencing a reactance effect. There is little evidence that reactance affects the diary's validity; however, as a significant element of PAMI-UK is staff reflecting, the diary entries may assist staff with the reflective process. The participants in the Day and Thatcher study (2009) used the diary entries similarly to reflect on their previous experiences and thoughts. The study's authors highlighted that as a result, during analysis, awareness should be maintained, and researchers should consider how reflectivity may influence subsequent entries.

#### 4.2.10.3 Residents' Experience Questionnaires

The primary researcher designed the residents' experience questionnaire to collect data on the residents' experience of staff interacting with them using PAMI-UK (Appendix 18). The questionnaire collected data on the resident's enjoyment engaging in the music, their preferences for the different skills, changes they would like to see and their views of participating in the study. Residents completed the questionnaire with assistance from care staff. However, it was only completed by participants with sufficient communication ability. As dementia can impair residents' abilities differently there was no prior expectation of the data collected in this questionnaire.

#### 4.2.10.4 Reflective Sessions

The reflective sessions aimed to collect data on the staff's experience of implementing PAMI-UK and the impact of skills on residents and staff. As the sessions were guided by staff's experience there was no prior expectation of the specific information collected. However, in general, information on the staff's experience of using the skills, issues concerning implementation, the manual's usability, lived experience descriptions, and issues with specific skills was collected. (Additional information is available in section 4.2.3 intervention). The primary researcher recorded all sessions bar one, due to annual leave, which was recorded by the PI (OM). Sessions were recorded on an Olympus WS-852, a university approved audio recorder. Each session lasted approximately 40 minutes.

#### 4.2.10.5 Interviews

Staff participants were invited to attend a post-intervention interview to discuss their experience. Interviews were scheduled during the last reflective session. The interviews were semi-structured with a topic guide used, but interviewers could ask additional questions based on responses. (Appendix 15). Either BW or BS delivered the interviews via Microsoft Teams. Interviews were recorded on an Olympus WS-852.

Although face-to-face interviews are considered the gold standard interview method (Saarijärvi & Bratt, 2021), interviews were completed online owing to the COVID-19 restrictions. When restrictions were lifted interviews remained online for consistency. Using a video conference call to conduct the interviews was selected as this allowed for the closest simulation of an in-person interview (Saarijärvi & Bratt, 2021). Conducting and transcribing video interviews can be more challenging due to internet connections and low-quality audio. Staff were encouraged to complete the interviews in a quiet room in the care home, with minimal distractions to improve the audio quality. The use of face masks during the interviews also affected the sound quality, with the mask making it challenging to decipher speech during the transcribing stage.

#### 4.2.11 Analysis

#### 4.2.11.1 Demographic statistics

Data collected from the resident, staff, and care home demographic questionnaires and residents' DSRS scores were entered into SPSS Statistics for windows, version 27 (IBM Corp, 2021) and the mean and standard deviation (SD) was generated.

#### 4.2.11.2 Transcribing

Before analysing the reflective sessions and interviews, the audio recordings required transcribing. All audio files were transferred to a password-protected file on a password-protected computer immediately after the session and deleted from the audio recorder. The University of Nottingham Automatic Transcribing service was used for the first transcribing stage. The service is secure and meets GDPR guidelines and has an accuracy rate of 70-99% (University of Nottingham, 2022). To use the service, recordings needed to be in the format Mono MP3, Audacity was used to convert the recordings (Audacity Team, 2021). Two reviewers independently reviewed the transcripts to determine accuracy. The first stage was to listen through the recording, assign an identity code to each speaker. One reviewer went through the transcript and changed any incorrect transcriptions before a second reviewer went through to confirm the first reviewer's accuracy, changing any inaccuracies that arose. The reviewers ensured names and any personal information identifying the residents, staff, or care homes were removed. If a participant's name was mentioned, their identity code was used. If another staff member not participating in the study was mentioned, their job title replaced their name.

#### 4.2.11.3 Thematic Analysis

NVivo Version 12 (QSR International, 2018) was used to conduct a thematic analysis. Thematic analysis was selected due to its flexibility and entails identifying, analysing, and reporting themes within the chosen set of data (Braun & Clarke, 2006). A theoretical approach was taken where themes were generated based on the research aims and questions set at the beginning of the project. Braun and Clarke's (2006) six steps for thematic analysis were followed.

#### 4.2.11.3.1 Braun and Clarke's Six Steps

# Step 1 Familiarising yourself with the data

The two PAMI-UK facilitators who conducted the interviews also transcribed and conducted the thematic analysis, allowing them to immerse themselves in the data from the beginning. Step 1 began during the transcribing stage when both researchers (BS & BW) read through the transcripts multiple times to check for accuracy. Once the transcripts were finalised the researchers read the transcripts again, noting initial thoughts.

### Step 2 Generating initial codes

The two researchers independently worked through each transcript generated initial codes using Nvivo. After generating the initial codes, the two Nvivo files were exported into one to assess the inter-reviewer reliability. Merging the two files allowed the reviewers to view all the codes in one place. The codes were exported to a Microsoft Word file, where descriptions for the codes were included to assist with generating themes.

#### Step 3 Searching for themes

BW and BS reviewed the codes from the first two steps to generate initial themes by clustering relatable codes together. The two reviewers independently searched for themes and separately documented codes that were relatable.

# Step 4 Reviewing themes

The reviewers compared their themes and worked together through discussions to develop one set of themes that represented the important elements of the data collect. Once the two reviewers agreed, they were shared with a third reviewer (OM) to review. OM was not involved in the data collection stage providing an objective viewpoint to the analysis process.

# Step 5 & 6 Defining and naming themes and producing the report

BW and OM generated the final themes and subtheme names through discussions ensuring the themes represented the data collected and related to the study's research question.

# 5. Manual Field-testing Study

# 5.1 Introduction

The next stage of the cultural adaptation frameworks was to review the adapted manual version 1 with stakeholders and to use the data collected to revise the intervention. The manual field-testing study allowed the researchers to investigate the use of the manual to ensure that it was appropriate for the intended setting and audience. As there is limited research on PAMI, the study also provided a greater understanding of the use of PAMI-UK in care homes. The data collected during the study allowed the researchers to alter the manual based on the stakeholders' feedback.

# 5.1.1 Aims

- 1. To assess the PAMI-UK manual's appropriateness, usability, and readability for UK care staff to ensure appropriate cultural adaptation of PAMI-UK
- 2. To explore staff's experience of using PAMI-UK to investigate the clinical appropriateness of PAMI-UK
- 3. To investigate the factors influencing the implementation of PAMI-UK in care homes
- 4. To field-test the study design to ensure suitability for care homes

# 5.2 Methods

An overall detailed methodology description is available in Chapter 4, the methodology detailed below highlights the specific details for the manual field-testing study.

# 5.2.1 Study Design

This study is the first stage of a two-stage evaluation of the PAMI-UK intervention to review the cultural appropriateness of the adapted PAMI-UK in a real-life context in the intended setting with stakeholders. The qualitative exploratory study consisted of interviews, reflective session transcripts, diary entries, and residents' experience questionnaires. The data collected in the study assisted with the alterations of the PAMI-UK training tool.

# 5.2.2 Setting

The study ran between September 2021- January 2022 within three Lincolnshire care homes, recruited through the Lincolnshire NHS Trust In-Reach pilot scheme. All care homes were approached by RF, who reviewed the care homes eligibility and inviting them to participate. Two care homes had a CQC score of 'good' and the third had a scoring of 'requires improvement'. (Chapter 4 provides more details on the settings).

# 5.2.3 Participants

The researchers aimed to recruit nine staff members and nine residents with dementia, three from each care home. The staff and residents were recruited separately and paired into dyads post-recruitment.

Staff were eligible to participate if they:

- were aged 18+
- had the capacity to consent
- were permanently employed at the participating care home for at least 6 months prior to the research and planned to remain there for the study duration

- worked a minimum of two shifts a week to ensure sufficient time to implement PAMI-UK
- had the ability to read, write and communicate fluently in English
- assisted residents with activities of daily living or leisure activities
- were not participating in other psychosocial interventions research

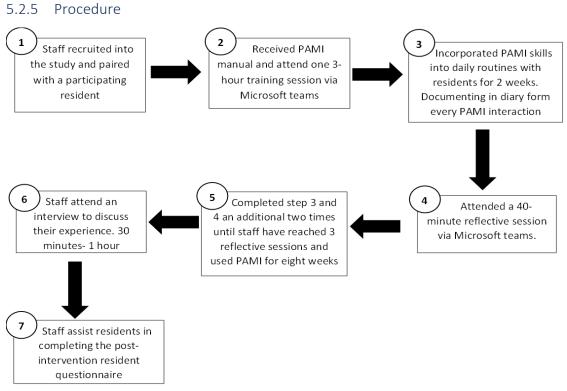
Residents were eligible to participate if they:

- were aged 18+ (no upper limit)
- had a diagnosis of dementia per the ICD-11
- had capacity to consent in accordance with the Mental Capacity Act 2005 or have a consultee if deemed to lack capacity
- had lived at the participating care home for at least 6 months with plans to remain there for the study duration
- had sufficient hearing or use of hearing aids
- had regular interactions with a participating staff member
- were not participating in other psychosocial intervention research

Nine staff and nine residents expressed an interest. However, only eight care staff were eligible. As no other staff expressed an interest; the ninth resident was unable to participate resulting in eight dyads being recruited.

# 5.2.4 Intervention

All participating staff were trained in the PAMI-UK intervention. The intervention consisted of a paper copy of the manual version 1 (Appendix 3 & 4), a 3-hour group interactive webinar (Appendix 4) and 3 40 minute fortnightly reflective sessions. The training and reflective sessions were delivered online with all participants from the same care home completing sessions together when possible. (Chapters 3 and 4 discuss the intervention in more detail.)



*Figure 5.1 A flow diagram presenting the procedure for staff participants in the manual field-testing study* 

Figure 5.1 presents the procedure for staff in the manual field-testing study. The study ran for ten weeks in each care home, with PAMI-UK being implemented for eight weeks.

## Stage 1

The In-Reach Practitioner advertised the study to In-Reach care homes who met the eligibility criteria. Welcome packs containing the managers letter, and staff and resident welcome letters were sent to the managers of interested care homes via post. Managers were asked to introduce the study to care staff and residents and distribute the participant introductory letters. Interested individuals were provided with a participant information sheet and consent form and a consent meeting was organised with RF. (Chapter 4 provides more details on recruitment and consent.) During the consent meeting residents' capacity to consent was assessed, for residents deemed to lack capacity a consultee was appointed, who received a

consultee pack. At the end of the recruitment stage participating staff and residents were paired into dyads.

### Stage 2

At the study beginning, staff received a paper manual, care staff and resident demographic questionnaires, a diary entry form, the dementia friendly demographic questions form, and the DSRS via post. Staff were asked to complete the questionnaires and the DSRS before the training. Each care home completed a care home demographic questionnaire. The care home managers were required to provide a care home email address to be used on the Teams channel to allow staff to access sessions. Care home emails were used to ensure that personal emails were not required. All three care homes decided to complete the training in one threehour block, with all staff members attending the same session.

## <u>Stage 3, 4 & 5</u>

After completing the training, PAMI-UK was implemented for eight weeks. During this time, staff documented their experience using the diary entry form. The use of PAMI-UK in their routine was at the staff's discretion. Staff attended fortnightly reflective sessions to reflect on their experience and gain guidance for the next fortnight. During the sessions the researchers monitored the study progress, including sufficient documents and any issues or signs of distress. Staff were expected to complete three reflective sessions.

### <u>Stage 6 & 7</u>

At the end of the study, staff attended an interview to discuss their experience. A post-intervention resident questionnaire was sent to care staff to complete with residents with sufficient communication ability. Each care home received a participation certificate and study results summary, and staff members received a certificate for completing the PAMI-UK training.

#### 5.2.6 Data Collection

Qualitative data was collected through diary entries, reflective session transcripts, resident experience questionnaires and staff interviews. (More information about the data collection available in Chapter 4)

## 5.2.6.1 Diary Entries

Staff were expected to complete the diary forms after each PAMI-UK interaction with their resident. The entries collected data on skill frequency, type of skill used, length of time, resident's reactions, and effect on interaction.

## 5.2.6.2 Reflective Session Transcripts

All participants were happy for the reflective sessions to be audio recorded. Although they had less structure than the initial training, each session mapped loosely onto one of the three main PAMI-UK elements. The facilitator aimed to explore each element to consider how staff implemented the skills and whether further guidance was needed. Staff were encouraged to create lived experience descriptions to verbally articulate their musical interactions. Data collected in the reflective sessions consisted of issues, lived experience descriptions for specific interactions, and PAMI-UK implementation.

## 5.2.6.3 Residents' Post-intervention Questionnaires

The residents' post-intervention questionnaire collected data on the residents' experience of staff interacting with them using PAMI-UK. The questionnaire collected data on the resident's enjoyment engaging in the music, their preferences for the different skills, changes they would like to see, and their views of participating in the study. Residents completed the questionnaire with assistance from care staff if they had sufficient communication abilities.

#### 5.2.6.4 Staff Interviews

The staff completed a 30-minute semi-structured interview post-intervention via Microsoft Teams. One of the two PAMI-UK facilitators (BW or BS) conducted the interviews and followed a topic guide. All participants were happy to be audio

recorded. The interviews collected data on the PAMI-UK manual's usability, suitability, and readability.

### 5.2.6.5 Returning of Documents

Each staff member received a sealable envelope with their study documents which they used to return their completed documents. At the end of each study the In-Reach Practitioner arranged with the care home for her to attend the care home to collect the participants' documents and distribute the participation certificate. The In-Reach Practitioner then sent the completed documents to the research team by post.

#### 5.2.7 Analysis

The data collected from the staff, resident, and care home demographic questionnaires and residents' DSRS scores were entered into SPSS Statistics for Windows, version 27 (IMB) and the mean and SD was generated.

The reflective sessions and interview audio recordings were transcribed before the two researchers (BW & BS) independently analysed the transcripts. The transcripts, diary entries and resident's post-intervention questionnaires were all analysed using thematic analysis (Braun & Clarke, 2006). Carers were coded as C and then a letter and residents were coded as R with the corresponding letter to their carer. (Chapter 4 provides more detail on the analysis process.)

The researchers planned to complete frequency statistics and thematic analysis for the diary entries to explore usage trends. Only three diary entries were returned and had not been used regularly to document interactions. As the diaries had not been completed as intended the researchers decided to remove them from the results. Additionally, the researchers planned to complete thematic analysis of the postintervention questionnaire, however all the residents had limited verbal language making completing the questionnaire challenging, therefore there was not data to include in the results.

## 5.3 Results

Care home 3 dropped out during the recruitment stage leading to a fourth care home being recruited. Eight dyads were initially recruited from three care homes. Only five (63%) dyads completed all study elements. Two staff participants dropped out before training, one due to illness and one due to research anxiety. One staff member attended the training but did not attend any further study elements. The residents paired with the three staff were all withdrawn. One staff member did not return their study documents. From the five remaining dyads, one resident's consultee withdrew her due to hospital admission; as the resident was withdrawn post-intervention, the staff member completed the interview but only commented on their training experience.

Six out of nine (66%) reflective sessions were attended. Care Home 1 (CH01) attended two sessions, Care Home 2 (CH02) attended all three and Care Home 4 (CH04) attended one. Reasons for missing sessions included holidays, care home responsibilities, family illness, and forgetting the sessions. All staff members had a positive attitude towards music in dementia care. The level of music engagement and interactions varied between care homes.

## 5.3.1 Care Home and Participant Characteristics

All three care homes were classed as residential. Two were privately owned, while the third was charity owned. *Table 5.1* presents the care homes characteristics.

Care home number	Number of residents	Staff: resident ratio
CH01	41	1:5
СН02	44	1:4
СН04	26	1:6

Table 5.1 Care home characteristics, including the number of residents currently living in the care home and the ratio of staff to residents on a shift

Four of the five (80%) staff completed the staff demographic questionnaire. The staff participants were all females aged 28-50 with a mean age of 39.50 years (SD 9.33).

The years spent in dementia care ranged from 5 years- 32 years, with a mean of 13.7 years (SD 12.38) with all staff being employed at the same care home for this length of time.

The resident demographic questionnaire and DSRS were completed for four of the five (80%) residents. All residents were female aged 79-94 with a mean age of 85.25 years (SD 6.70). The years spent living at the care homes ranged from 1 year 8 months- 13 years, with a mean time of 6.70 years (SD 5.28). Dementia severity was reported as either moderate or severe (DSRS scores between 29-47). The mean total DSRS score was 35.50 (SD 14.62). Residents had limited verbal communication, with them using non-verbal, or answering yes/no questions. All residents had shown enjoyment towards music pre-intervention.

## 5.3.2 Results From the Diary Entries

Three of the five diary entries were returned. One participant documented 18 entries across eight weeks, and two documented five entries each. The diary entries displayed the same examples as those discussed in the reflective sessions. Due to the limited number of diary entries returned and lack of entries, optimal usage cannot be determined. The entries did indicate that PAMI-UK was most frequently used in the morning, particularly during personal care but was also used at other times. There was a mixture of the different skills used, and multiple skills were incorporated in the same interaction. Although the diary entries could not be analysed as intended the data collected influenced and supported the themes generated from the interviews and reflective sessions.

## 5.3.3 Results From Residents' Post-Intervention Questionnaires

All resident participants had limited verbal language, making completing the resident's questionnaire challenging. However, through gestures, one-word answers and behaviours, staff inferred that all residents enjoyed the study and increased music within the care home. They felt the music used was appropriate and liked expressed through gesturing, and phrases such as "Oh Wonderful".

## 5.3.4 Themes

Seven themes and 14 sub-themes emerged from the thematic analysis. The themes consist of the impact of PAMI-UK on staff, residents and the care home, feedback on the manual development, the implementation of PAMI-UK, and staff's experience participating in the study. Table 5.2 highlights the themes and subthemes.

interview transcripts				
Overarching themes		Subthemes		
1.	Staff experience of using PAMI- UK	<ul> <li>Using the PAMI-UK skills</li> <li>Changes to staff behaviour and mood</li> </ul>		
2.	Residents' response to PAMI-UK	<ul> <li>Changes to residents' mood and behaviour</li> <li>Unexpected or negative resident responses to DAMLUK</li> </ul>		
3.	PAMI-UK's impact on the care home practice	<ul> <li>responses to PAMI-UK</li> <li>Other staff</li> <li>Other residents</li> <li>Management</li> <li>Care home practices and atmosphere</li> </ul>		
4.	Improved interactions			
5.	Staff's views of PAMI-UK	<ul> <li>Staff's views on the manual</li> <li>Staff's views on the interactive webinar</li> <li>Staff's views on the reflective session</li> </ul>		
6.	Implementation of PAMI-UK	<ul><li>Facilitators</li><li>Barriers</li><li>Long-term implementation</li></ul>		
7.	Staff's experience participating in the study	• Long-term implementation		

Table 5.2 Overarching themes and subthemes generated from the reflective session and interview transcripts

## 5.3.4.1 Theme 1 Staff Experience of Using PAMI-UK

#### 5.3.4.1.1 Using PAMI-UK

Two of the three care homes felt they used PAMI-UK skills pre-training. However, when discussed further, it was uncovered that staff used music in general but not PAMI-UK skills. CH01 was the most experienced in music pre-training, with them already implementing PAMI-UK like skills, including cueing. Initially, the CH01 staff felt that the training was not providing new knowledge. However, as the reflective sessions progressed, they highlighted areas they had not previously considered including the sound environments.

## "You're more aware of things like the environment sounds, that's one thing I did never really thought of" CH01 CA interview

Awareness of the sound environment could improve the implementation of other musical skills they already use. Additionally, the participant felt that the training made them more conscious of using PAMI-UK when entering a situation.

"I do think of PAMI... It's in the back of my mind thinking, what else can I do or how can I come across better? .... Should I mirror their tone and the way they're speaking?" CH01 CA interview

CA was making a more conscious decision to use PAMI-UK. Pre-PAMI-UK staff may have used music in specific situations, but the training had led the individual to think about how PAMI-UK can be used in every situation and the most appropriate skill to use.

All participants demonstrated attempting skills from all four PAMI-UK elements, with a range of success. Staff tailored the intervention to meet the resident's needs, impairments, abilities, and music preference to ensure person-centred care.

## PAMI-UK element 1: The Voice

Pre-training, staff had not considered their voice's impact on interactions. Staff members who identified their volume as loud consciously attempted to adapt this during training. "It makes you think when you're into somebody's bedroom how you actually are... Cause I'm quite a loud person as you might recognise. And I've actually calmed down. I'm quite quiet in the mornings now." CH02 CC interview

PAMI-UK led CC to be more conscious of her tone and volume, as she felt her accent could be interpreted as abrupt despite trying to convey a different message. All staff members increased their awareness of their voice and adapted appropriately. However, CA seemed to also become more aware of her resident's voice and worked to mirror the resident's voice and mood.

"One thing that I did do with my lady was I was giving her medication this morning. And I wasn't singing, but I was talking to her like the tempo and pitch and stuff that she did. so like, 'Hello CA (high pitch sing-song tone)' and then, 'you look lovely (high pitch sing-song tone)'." CH01 CA Reflective session 3

By mirroring RA's tone, CA was able to encourage the resident to take her medication, improving the task acceptability.

## PAMI-UK element 2: Framing

CH02 found cueing challenging to incorporate, however, they found creating a safe environment effective.

"I set up the bath for my lady who's ... fiercely independent with personal care. And she's getting to the point in life now where she does need a bit more extra help... So, I set the bathroom up all nice. I made it all romantic and got myself a little Chopin playlist off of YouTube. And just some random classical music." CH02 CD Reflective session 1

Pre-PAMI-UK RD had only experienced three successful but unpleasant bath times in five years. In the quote, CD created predictability and a safe environment by ensuring the required equipment and products were ready beforehand. A relaxing classical playlist was selected based on the resident's music preferences ensuring that CD would remain calm. Although CD reported struggling to incorporate cueing, she demonstrated the skill by using the same classical playlist during a different bath time, with similar outcomes.

On several occasions, CH02 demonstrated potential cueing if they continued to use the same music for the specific task.

"I did work with the other lady... I'm not used to doing her personal care. And obviously she's not used to... my face. She was in a terrible mood... So, I thought I'm going to put my music on.... All the Leaves are Brown... I was trying to talk about autumn and all the leaves outside of the window.... And she was humming along still giving me side-eye... So, she allowed me to help with choosing clothes and she allowed me to let get herself washed and ready... And reluctantly came with me to go get some breakfast but later on in the day... she kind of imprinted on me and she was following me around saying you're the girl with the music in her pocket." CH02 CD reflective session 2

Due to COVID-19, CD has switched to a different unit with different residents. Although she only used the song once during the study, repeated use would demonstrate cueing. Additionally, CD realised how the song also orientated the resident to the time of year. A cue the PAMI-UK facilitators had not considered was the association residents created between their staff member and music. As highlighted in CD's quote, despite the resident being initially cautious of her, the resident was actively looking for CD by the afternoon.

Both CH02 staff members reported that their paired residents had also created an association between them and music.

"My resident now looks at me, and she starts dancing even if there is no music." CH02 CC interview

The association between the staff member and music was not reported in any other care homes.

All staff developed a deeper awareness of the sound environment, with some making changes to improve. CH reflected that pre-PAMI-UK, the television was switched on in the morning, and combined with individuals talking, created an unpleasant sound environment. The training led to CH switching off the Television, removing unnecessary noises, and introducing relaxing music to the main lounge. Some staff were aware of the unnecessary noises but felt unable to make changes, predominantly when it relied on non-participating staff behaviour change.

## PAMI-UK element 3: Balancing

High agitation was experienced regularly by some residents.

"I know with RB upstairs... If I hear her from down here... I can go up put my hand on her face and start singing, and she'll stop straight away what she's doing and join in." CH01 CB interview

CB recognised RB's high arousal and selected appropriate music to regulate the arousal levels to a state where the resident could connect with others through song.

CD recognised the need to consider appropriate music based on the resident's arousal during a situation between two residents.

"Two of the residents don't see eye to eye... they had a bit of a clashing of heads where my lady was trying to tidy up... then one cup got dropped... And then we nearly had a fight. But I hummed. Because I thought singing it might be a bit aggressive. So, I hummed, 'Show Me the Way to Go Home'. And kind of hummed her to her bedroom...By the end of it she's (slapping rhythmically) like this on her knees, telling me, like show me the way to go home" CH02 CD reflective session 1

CD recognised that singing while her resident was highly aroused may have heightened her agitation; therefore, hummed to gain RD's attention without increasing arousal levels. CD removed RD from the situation and reduced their arousal level to a level where the resident and care staff could connect through music.

The previous two balancing examples demonstrated when the resident was already highly aroused. Balancing can be used in agitation-induced situations, such as personal care to prevent agitation.

"With my lady, I was put like calming Cliff Richard on. And sort of brought her around. And she sort of woke up. And she was quite bright." CH02 CC interview

By removing the initial talking and playing calming music, RC woke up slowly, allowing time to process the situation and start the day with a balanced arousal.

## PAMI-UK element 4: Connecting

Pre-training, all staff reported a good relationship with their resident. However, staff felt the relationship deepened during the study.

"She couldn't really- not get close to her. But now she likes a cuddle every morning. She's in that routine." CH04 CH interview

RH began to enjoy physical touch, such as handholding and cuddling because of the PAMI-UK skills. Despite neither party using verbal communication, they connected, highlighting the importance of non-verbal communication.

Although not all staff commented on developing deeper relationships, all staff reported using PAMI-UK to connect with residents.

"I was just singing- yodelling around the house. And this one resident, he did it back to me. Had the biggest grin on his face ... We was just yodelling all over the place and honestly the smile on this man's face was amazing" CH01 CA interview

Once again, despite no verbal communication, CA connected with a resident leading to increased smiling from both the resident and staff member resulting in a positive and enjoyable experience for all involved.

Through the training, staff discover and explore the concept of attunement. When staff attune to residents, they are present with the other person's experiences to sense their rhythm and affect to create a feeling of connectedness.

"I tend to know what these people like are feeling... Like now when RB says some- something. Cause he just makes sounds. And I seem to know, not what he's thinking, but what he wants. And then I give him it and he's had it... His wife said this morning, 'that it's amazing, because that's really being in tune with him'." CH01 CB Reflective session 3 Despite being non-verbal, CB interpreted the resident's communication and provided for his needs. The resident may feel more understood by the staff member leading to the resident searching for them when requiring something.

"She seems to want to come and talk to you... she's not always verbal, not always understand what she trying to say. She used to come and try to speak to one of us. But when she sees CD, she sort of aims towards CD more now" CH02 CC reflective session 3

Pre-PAMI-UK, RD spoke to any staff member. However, since the training, she was more likely to interact with CD. The staff demonstrated the essentialness of attunement when residents are non-verbal. These interactions require awareness of subtle communication and for staff to interpret and respond appropriately.

## 5.3.4.1.2 Changes to Staff Behaviour and Mood

All staff highlighted changes to their behaviour and mood in response to using PAMI-UK. Staff experienced increased confidence, in particular, feeling less self-conscious about singing or acting silly. According to CB, CA rarely sang pre-PAMI-UK. After the training, CA sang without overthinking beforehand, highlighted by the fact that she would sing when walking through the home, even when not working directly with a resident. Staff experienced a change in their mood with them reporting increased happiness.

The staff discussed the stressfulness of care homes, especially when residents experience high anxiety, agitation, or resistance to care. As a result, staff can experience high levels of frustration and anxiety when faced with challenging situations. Using Framing and Balancing skills during personal care or periods of agitation led to staff feeling more relaxed and happier owing to residents' behaviour change. CC suggested that a common musical interest contributed to the staff's mood and staff-resident relationship.

*"I'm happier. I feel that it's not only lifts my lady's mood, but mine as well. Because I quite like most of the music that she does. So, we're both singing along, and we're both smiling and fun" CC CH02 reflective session 1*  CC felt happier since using music expressed through singing, smiling, and generally having fun together. When PAMI-UK improved challenging situations, staff felt a sense of pride.

"I was so proud myself... If she does have like a wash, it's a reluctant wash, but she enjoyed it... I really made the effort" CH02 CD reflective session 1 CD scheduled time to create a safe environment, as a result, when the bath was enjoyed, CD experienced a sense of pride in improving the resident's experience.

Staff reported improvements in their daily practices, particularly coping better with previously challenging situations. Pre- PAMI-UK staff experienced resistance to care and verbal and physical aggression, making completing tasks challenging and negatively affecting staff such as feelings of helplessness. In some scenarios, music did not improve the resident's response but worked as a coping mechanism for staff.

"But if someone needs, in their best interest to have some personal care... we just have to do it. And whatever comes our way, you kind of have to deal with that as well. But sometimes singing, can kind of just drown out some of the... unwanted noise that we might be getting... We can kind of sing, we can kind of hum... try to sing something to distract her. It doesn't always work, but it means that we're not hearing these things.... It's not always about helping the resident. But sometimes we might need a coping mechanism" CH02 CD Reflective session 3

PAMI-UK aims to support staff by providing the skills, such as the one highlighted in the quote to manage challenging situations such as high resident arousal.

BM reported that PAMI-UK highlighted the person behind the diagnosis.

"But more like themselves instead of being a dementia patient... They just seem more that they're their selves." CH04 CH interview

Introducing music into morning care to calm and relax residents resulted in residents being more like themselves allowing staff to see the individual instead of their diagnosis.

#### 5.3.4.2 Theme 2 Residents' Response to PAMI-UK

#### 5.3.4.2.1 Changes to Residents' Mood and Behaviour

Staff documented improvements in residents' BPSDs including mood, with residents enjoyed the increase in music. Residents were observed humming to themselves outside of music activities which was interpreted as them being happier and content. Increased happiness was observed through increased laughter, smiling and dancing.

When music was used to regulate arousal, fewer agitation incidences occurred, when they did occur staff could reduce agitation quicker.

*"If she's irate and is having a distressed reaction..., she will actually come towards us. And we will actually just put some music on. And it just calms it down." CH02 CC Reflective session 2* 

RC recognised when she was agitated, and that CC had the means to alter the negative emotions. For residents unable to interpret their emotions, staff recognised their and used music to alter their emotions. Agitation was common during personal care or transfer when residents could not comprehend the situation.

"This lady can't move herself, we have to lift her with the stand aid. Normally that is a no go... With the music on, she's absolutely fine... Sometimes we will put the music on ready... she's concentrating more on what's being played than what we're actually doing." CH04 CH reflective session 1

Music during the task ensured RH did not experience distress or agitation. Playing the music prior to her entering the room led to the residents' emotions remaining constant throughout the transferring process. Music during tasks also improved task efficiency and created a more positive experience for residents and staff.

PAMI-UK increased residents' awareness and attention leading to more interactions.

"We've got one lady that usually just sits there doing nothing, and you'll actually see her now without any music going like this (demonstrates actions) and happy... and so I think it's made her a little bit aware." CH02 CB Reflective session 3

Greater awareness of their surroundings may have contributed to increased resident participation and engagement. Alternatively, increased participation and

engagement may have contributed to the improved alertness. CB also felt that engagement lasted for longer after music activities.

CB used PAMI-UK during mealtimes, which led to improved mood, maintained attention, and increased food consumption. CB created a dinner song and whistled behind her mask to maintain RB's attention, which led to laughter.

During the intervention, staff did experience crying from some residents. The training had explored allowing residents to express repressed emotions and memories. However, in some instances, staff felt the crying was a negative response.

"That when I had a little slow dance with her and she stopped, stood back and went like this with her eyes (gestured wiping her eyes) .... She didn't cry but if I had carried on, she may have cried." CH02 CD reflective session 3

Whilst this may be a negative response to PAMI-UK practise, whether RD was experiencing distress was not confirmed by CD. In another resident, an emotional response was tiggered by music playing, which subsided when the song stopped.

"A song came on and she just sobbed.... I did ask her why she was crying... And she said just, 'I don't know I'm just crying'. She was alright after the song finished. So, it obviously just triggered something." CH02 CC Reflective session 2

CB demonstrated recognising the resident's need to cry to release emotions, demonstrating attunement to their resident.

"CL's lady, 'Can't help Falling in Love'... She'll cry.. She loves it so much. So it's a happy cry. ...I don't think she'd want you to stop it singing it." CH01 CB Reflective session 1

Care staff noticed memory improvements, with residents knowing the song lyrics despite struggling with other tasks.

"I can play bingo. And I was on one line still an hour and a half because they couldn't dab the number. But then they know every song" CH01 CB Reflective session 3

Not only could residents recall lyrics, but they were also able to recall other information relating to the song, such as the artist.

## 5.3.4.2.2 Unexpected Resident Responses to PAMI-UK

On occasions, responses to interactions were unexpected or not the desired outcome. CD attempted to use the same bath time classical music playlist during an activity to engage RD. Despite previous success, the music led to RC being disengaged and over stimulated.

Some staff felt the success of PAMI-UK varied between days and depended on the resident's moods.

"Sometimes it won't work. If she in that sort of mood, it won't work. But that nothing unusual... Sometimes you just got to leave her to her own devices till she calms down" CH01 CA Reflective session 1

CA believed her resident sometimes needed alone time to calm down and using PAMI-UK could cause more agitation.

CB also discovered timings affected some residents. Even though she attempted Balancing by aligning the music to residents' mood, she could not wake them after breakfast.

"I do struggle first thing in the morning because they've all asleep when I come in.... It doesn't matter how much I sing, I can't stimulate them in the morning" CH01 CB Reflective Session 3

CA explained broken sleep during the night may be a potential explanation for Balancing being ineffective.

Residents' other conditions and illnesses could explain unexpected responses to an interaction.

*"Just once they didn't want to do it. But then they had got UTI." CH01 CB Reflective session 3* 

"Our ladies have actually had chest infections in the last couple of weeks. So obviously you can't sort of put music on, cause that's not gonna make them feel better." CH02 RS Interview

In the first quote, RB refused to participate in a music activity; CB felt that a Urinary tract infection (UTI) could explain the unwillingness. In the second quote, CC did not attempt any PAMI-UK skills because she felt it was inappropriate to use music, as it would not improve the illness.

Using music not tailored to the resident's preferences may be another explanation for unexpected responses.

"We were playing like the wartime music, like the sing-along wartime music... Everybody liked it by my lady didn't... She just wasn't singing along and sort of moving and smiling like she did as soon as we put Cliff on." CH02 CC Reflective session 2

RC only responded positively to Cliff Richard. When other music was played, she became disengaged.

## 5.3.4.3 Theme 3 PAMI-UK's Impact on the Care Home Practice

Although the study only recruited a small sample size, the intervention impacted non-participating residents, staff and the overall care home practice and culture.

## 5.3.4.3.1 Non-Participating Staff

Non-participating staff attempted to include some PAMI-UK techniques into their practice.

"Without telling anyone about the programme, what I noticed was that the staff started like copying without knowing they were doing it." CH01 CB Interview

CB observed that staff subconsciously attempted PAMI-UK skills, despite not having knowledge of the intervention. Staff in other care homes were more conscious about including PAMI-UK, with some participants suggesting skill to other staff that could benefit residents.

*"Everyone is enjoying it, it's not just me and CG... Everybody sort of jumping on and putting music on" CH04 CH Interview* 

When CH observed the benefits during transfer, she considered asking the day staff to incorporate the technique to maintain consistency.

Although non-participating staff attempted to incorporate PAMI-UK into their routine, they could also prevent staff from using PAMI-UK. The CH01 participants felt they could not make changes to the sound environment to reduce the loudness of the care home because the non-trained staff were unaware their behaviours were affecting the environment.

"You can hear the carers. They can stop the activity. They don't realise they're doing that... I feel like saying can you be a bit quieter. But I don't want them getting on me." CH01 CB Reflective session 1

CB felt unable to make changes for concerns about other staff responding negatively to her request. CB would sing louder to compensate for the carers' volume leading to a noisier and a low fidelity (Low-fi) sound environment. CH01 concluded they were a loud home without providing any suggestions for improvements.

## 5.3.4.3.2 Other Residents

Although paired with one resident for the study, care staff also provide equal care and attention to multiple residents. Many of the PAMI-UK skills took place in communal areas: therefore, consideration of other resident's needs and preferences was vital. Many non-participating residents were interested in the activities, leading to staff including them in the sessions.

# *"It started off with just my resident sort of the first few times. And as it's gone on everybody's joining in" CH04 CH Interview*

CH highlighted that she introduced music into the lounge to regulate RH's arousal, as it was in a communal space other residents also experienced the balanced arousal state.

Once staff observed residents benefiting from PAMI-UK, they started introducing the skills to other residents.

"But with like setting the scene and the framing..., I've definitely have used that with other people and got quite nice results." CH02 CD Interview

"When I get five minutes, I'm definitely going to try and get it in everybody's care plan" CH01 CA Interview

When CD incorporated the skills with other residents, similar positive results were observed. CA aimed to create a PAMI-UK care plan for each resident to monitor music engagement and preferences. CH04 also found the music care plan vital, and their manager had introduced a music section into their care plans documenting preferences and reactions to music.

Although including non-participating residents yielded positive results, some staff experienced challenges from non-participating residents. CH02 experienced several scenarios where different residents' needs and preferences conflicted.

"Just be aware of your audience...because obviously we're targeting towards our residents... but obviously we have to be aware of our surroundings... We've got a lady in the big main lounge where we put the YouTube on the telly... It's quite near to another lady's room who then came out and she was like, 'oh what's all this noise'." CH02 CD Reflective session 1

Not all individuals enjoy music, and CH02 recognised that all residents' music preferences need considering which may affect the location or time of PAMI-UK activities. CH02 experienced another challenge at breakfast when some residents were benefiting from Framing, whilst a couple wanted silence to enable conversation between themselves.

"We tried to set the ambience for everybody. But we have a couple that just like to sit and talk amongst themselves. And the background noise, the chattering, the music, everything going on obviously would be quite a distraction." CH02 CD reflective session 1

There was a challenging discrepancy between accommodating those who enjoyed the silence, and those who required background music to create a suitable sound environment. Staff had to learn to explore compromises to ensure all residents' needs were met.

## 5.3.4.3.3 Management

Management was supportive in all three care homes leading to them making accommodations for staff to attend training and attempt PAMI-UK skills. In CH04, the management reported to the care home company headquarters the impact of PAMI-UK.

"We had a staff meeting just before Christmas, and the big bosses was there. So, the manager sort of said, you know we are doing this. And she was really positive about it. And I think we will definitely carry it on after everything finishes" CH04 CH interview

Staff suggested the management support would lead to PAMI-UK continuing after the study and for the care homes to make changes to practice.

## 5.3.4.3.4 Care Home Practices and Atmosphere

Staff experienced an overall change in the care home atmosphere and practises. CB felt PAMI-UK had *"brought the home alive" (CH01 CB Interview),* with staff and residents becoming more vocal. CH, a night carer, especially observed changes in the morning, a time she reflected as being stressful and time sensitive.

"I think in the morning it's crazy... you don't have a great deal of time... And with the music on, we don't feel rushed. Because you've not got the noise of the news or whatever on the telly. You have got all that sort of going on, and then you're sort of thinking what you gotta do. And then you can hear the news, and it's all, 'Oh God, what's going on now'... The whole place, it just seems a lot more relaxed when there that little bit of music on" CH04 CH Reflective session 1

The sound environment in CH04 was causing increased staff stress, which as a result negatively affected resident. Pre-PAMI-UK staff automatically switched on the news which CH increased staff stress due to hearing negative news stories. The multiple noises made concentration on task challenging. Switching to music relaxed residents and reduced staff stress making it easier and more pleasant to complete routines.

Music during personal care tasks improved task efficiency, with tasks being completed quicker, smoother, and a more pleasant experience for staff and

residents. Improvements in task efficiency had an overall effect on the care home atmosphere.

"... the manager was saying, you know, for everyone to like trial it because it not only helps the resident, but it helps us. Because if the residents are not aggressive or anxious or anything like, that it makes our job easier to help them." CH04 CH Interview

Non-participating staff and managers recognised the residents' behaviour changes resulting from PAMI-UK. Reduction in residents' agitation and improvements in staff's stress and time pressures overall led to a better care home atmosphere for residents and staff. The improvements in residents' behaviour resulted in staff experiencing a better workday.

## 5.3.4.4 Theme 4 Improved Interactions

All staff reported increased frequency and quality of interactions between residents and with staff. PAMI-UK led to closer connections between residents and improved communication abilities.

"It's brings everybody, like the residents especially, that bit closer. Because if they're sort of all sitting in the lounge together and one says, 'well I'd like this song on.' And the other one next to them would say, 'well I like that, and I like that music or that person'." CH04 CH Interview

Music listening initiated conversations between residents by discussing their music preferences. Additionally, the activity allowed staff to discover residents' life history and update the music care plan to ensure person-centred care.

CH02's staff discovered that music can be a common interest that helps residents be civil and get along.

"The two ladies... that don't see eye to eye... I wouldn't say they got on. But they put their differences aside while the music is on" CH02 CD Reflective session 3

Residents enjoyed the music, which aided the two residents in being civil with each other. However, when the music finished, or non-preferred music was played, the two individuals would argue. Residents and staff demonstrated increased singing, verbal, and non-verbal communication. RA had limited verbal communication with emotions expressed through tone and repetition of limited words.

"She is verbal but not conversation-wise. She will be very repetitive with noises. So she would like say 'didili didilidum didili didilidum (sounds) all the time. And it was the tone and the volume of that how you would know how she was feeling" CH01 CA interview

CA recognised RA's noises as an attempt to communicate which she interpreted and responded to appropriately, demonstrating attunement. As the study progressed, RA's verbal language improved.

"She was actually saying words like 'happy'. Which she not done... 'You know, the lyrics. She started off on 'tappy, tappy' because that's what she says, to proper words." CH01 CB interview

Pre-PAMI-UK, RA used nonsensical words to express emotions. During the study, she began using more salient words relating to her emotions. RA was the only resident documented as experiencing improvements in verbal communication.

All residents experienced improved non-verbal communication, with staff demonstrating attunement.

"She was, you know, gesturing and dancing. She said- from what I can gather, cause she's non-verbal..., she said, 'my mum would be oh, oh, oh'. But my dad would be, 'laaah (sound)'. So, I'm guessing that her mum like classical music, but her dad thought it was rubbish." CH02 CD Reflective Session 1

RD began sharing her life history whilst CD bathed her. Gestures and sounds allowed the resident to communicate when verbal language was limited, while being attuned to the resident allowed CD to interpret the communication. CD's lack of classical music knowledge allowed the resident to teach her.

Although staff had a strong relationship with their resident pre-PAMI-UK, staff felt relationships strengthened during the study.

"They think wow, my person's here today... I think it's definitely helps build a bit of a bond. Although we did- We had a bond anyway.... But I feel like they literally come at us." CH02 CD Reflective session 1 A similar staff-resident relationship was experienced in CH04 since implementing PAMI-UK, where pre-PAMI-UK RH disliked physical touch but now enjoys daily cuddles.

Although relationships strengthened, CC suggested an initial bond was required for PAMI-UK to succeed.

"You've got to know your resident... Because I've not got the bond with CD's lady that she has. So, if I'd done that, she might not have reacted the same way." CH02 CC Reflective session 1

An initial trust and a sense of security between the resident and staff was required Pre-PAMI-UK as a foundation.

## 5.3.4.5 Theme 5 Staff's Views of PAMI-UK

Overall, staff displayed a positive attitude towards the intervention and enjoyed participating in training. They felt the intervention benefited residents, themselves, and the care home. Despite years of caring experience, all staff members gained new skills.

"We've been in care for so long, and honestly, you think.... you might know everything. But we've actually learned a bit more. Being musical people doesn't qualify you to go and play music at somebody, as we've learned." CH02 CD Interview

By the end of the training, staff recognised the difference between playing music and using music therapeutically. The staff could consider the factors that influenced musical interactions' success.

The staff voiced that PAMI-UK, and music were not appropriate in some situations. CD believed using music during end-of-life care was inappropriate.

"We have people on end-of-life and as much as a nice trickling sound of water CD might be nice for them in there maybe... You won't want to be going in there and humming things and singing things. Cause you need to be respectful" CH02 CD Reflective session 1

CD felt music and PAMI-UK in end-of-life care was inappropriate as singing and humming are not respectful.

Although PAMI-UK was explicitly developed for care home residents with moderate to severe dementia, CA believed being a dementia home meant using the intervention was different for them.

"Obviously, things are a bit different for us as we are a dementia home, and obviously, each individual person is different. Sometimes you might not be able to do the PAMI with some and not other." CH01 CA Interview

CA believed PAMI-UK was not suitable for all their residents with dementia, although she did not provide a reason why.

Staff who had used PAMI-UK like skills pre-PAMI-UK experienced pride in their skills being evidence-based and used by other professionals.

"That makes me feel quite proud that there's somebody out there thinking the same mind as me" CH01 CB interview

"Now it's actually put a label on it with like the songs, and we'll say you know, Like the toilet thing. Like we thought that was just something that we did, we didn't realise it had a label." CH01 CA Reflective session

Additionally, staff felt a sense of pride in being trained in PAMI-UK, which is

additional to the basic carers' requirements.

## 5.3.4.5.1 Staff's Views of the Manual

The manual was reported as informative and well laid out making it easy understand and access relevant information.

"I just felt relaxed that it was all there, the information was all there, and I didn't have to go rooting about or think am I doing this right or wrong" CH01 CB Interview

The manual was referred to as being self-explanatory and not challenging to follow.

Four out of five participants repeatedly consulted the manual when implementing PAMI-UK and felt they would continue to refer to it after the study ended.

"I found myself going back to it and referring quite a lot with it. The balancing, the framing to remember those. That's mainly. But the songs and things that are right at the back I found that quite useful as well." CH02 CC Interview CA and CB both found the example songs list a valuable reference. CA considered printing copies to have accessible in the staff's work areas to prompt the use of appropriate music.

Staff felt that the manual was accessible and considered different learning styles. Sectioning information into different coloured boxes improved the ease of locating specific information and aided staff in navigating the manual.

"The key of different coloured boxes and that sort of thing, I think that's handy." CH01 CA Interview

*"It does tell you at the front, doesn't it? The different information that you really need to know. And then the information that might just help you along like I found that quite helpful." CH02 CD interview* 

Highlighting essential information in grey boxes allowed staff to locate them easily when limited on time. CH typically struggles to learn through booklets but found the manual easy to understand with the accompanying webinar assisting staff to gained greater comprehension and provide guidance on areas unclear from the manual.

*"I found it quite easy to understand… I don't normally- If you show me yeah, fine. But if you give me a booklet or something. I'm a bit- but no… I thought it was really good, really helpful." CH04 CH Interview* 

When asked about improvements to the manual, one staff member felt no improvements were needed. While others provided minor suggestions, including blank pages for additional notetaking.

## 5.3.4.5.2 Staff's Views of the Interactive Webinar

The webinar was considered accessible and engaging, achieved through the videos and interactive elements. Staff found the included videos helpful and appreciated the different learning techniques that made the training accessible to individuals who struggled to comprehend written text. Having two facilitators run sessions was also suggested to improve engagement and ensured attention remained on the content.

CD appreciated the interactive face-to-face webinar, even though delivered via teams as she felt the format provided a more personal approach to the intervention.

"A bit more personal... To go in and, like this is my idea... I mean, it's probably been less so because of COVID, and you've not been able to actually come and meet us in person. But to like go off with someone's ideas just based on some paperwork that's flung at you." CH02 CD interview

CD voiced that she would have preferred in-person training and reflective sessions. However, remote learning via conference calls was sufficient during the COVID-19 pandemic. Having both the In-Reach Practitioner and PAMI-UK team available via email ensured remote learning did not hinder the staff's experience. Meeting the PAMI-UK team led to relationships developing between staff and the facilitators resulting in staff feel confident and trusting in implementing the researcher's ideas. While most would have preferred in person sessions, one staff member suggested that remote learning might have improved the accessibility and ease of attending training.

There were mixed opinions on the training length. Some found the three-hour training sufficient and not too long.

*"I think three hours was fine. Because if you did bit by bit, I don't know if you'd forget some of the first bit." CH04 CH Interview* 

CH voiced concerns over forgetting vital information or skills between sessions if split in two. However, some staff felt that three-hour in one session was too long.

"I think three hours was a bit in depth of the manual... breaking it up would have been a little better... Because three hours on your first, it was like whoo... two sessions... It wouldn't have been so in your face." CH02 CC Interview

CC believed the one training session led to a lot of information processing at one time. She would have preferred two sessions with time in between to process the material. Care homes were offered an option of two shorter sessions; however, all managers chose the 3-hour session.

## 5.3.4.5.3 Staff Views on the Reflective Session

Although staff found the manual and training easy to follow, the fortnightly reflective sessions were vital for monitoring and supervision. The session allowed staff to raise issues that had occurred during implementation or gain greater insight into struggling areas.

"I think even if there wasn't enough information for somebody say, or they didn't understand it, both of you were so approachable and that on the reflective sessions if we did have a problem, I feel like I could have asked you anyway." CH01 CA Interview

CA used the reflective sessions as an opportunity to gain clarity in misunderstood areas and felt comfortable asking for help when struggling.

The reflective session gave staff time to reflect on their work from the previous fortnight.

"Things I've done on the floor with residents, sometimes I've done it, and sometimes I've forgotten to actually write it down. So, the reflective sessions jog my memory" CH02 CC interview

CC sometimes used PAMI-UK but lacked time to document and reflect during her shift, due to time pressures and busy schedules. Attending the reflective session prompted her to remember musical interactions she had attempted. On occasions, staff attended sessions believing they had not implemented PAMI-UK that fortnight. However, as the facilitator guided staff, it became apparent that more PAMI-UK elements had been incorporated than they initially believed.

"It's easier to talk to you than it is to write it down. We can write little notes down just to jog our memories of what we've done and then go more in-depth with you and sort of you could ask us a question and it's like oh yeah actually I did do this" CH02 CC Reflective session 3

The sessions created reassurance and confidence that staff understood and

implemented the training correctly.

"It's like talking about everything that we've done and. Just reiterating that we're actually doing things okay, and helping, and making them happy." CH02 CC Interview

"it just backed up that we were doing it. Gave us a bit more confidence that we were doing things how we should be doing them." CH02 CC Interview

The opportunity to attempt skills before discussing their experience led to increased staff confidence and a willingness to experiment. Even staff who incorporated music skills pre-PAMI-UK benefited from the reflective session as the facilitators provided

reassurance and recognition of the staff's current abilities as highlighted in the second quote.

Staff appreciated having the opportunity and time to explore, reflect and share ideas. On occasions, staff suggested ideas their colleagues could attempt for a particular resident. Staff found it helpful to have an *"other pair of ears" (CH02 CD Interview)* to discuss ideas.

Overall, staff reported no reflective session changes. However, one participant was sad the reflective sessions were ending and would have liked additional sessions.

*"I don't think it's long enough... We want longer training... maybe four months" CH02 CC Interview* 

CC would have preferred for the reflective sessions to have run fortnightly for four months rather than the two months offered in this study.

## 5.3.4.6 Theme 6 Implementation of PAMI-UK

Staff successfully implemented PAMI-UK into routines demonstrated through lived experience descriptions in the reflective sessions, with PAMI-UK feeling natural to staff by the study end. Staff understood the training and could implement relevant skills while also considering the implementation of skills in other areas of the care home.

## 5.3.4.6.1 Facilitators

The lack of specialist equipment required was identified as a facilitator of implementation. Staff could use either their voice or equipment already owned by the care home. The portability of playing music through a phone or portable speaker increased the accessibility of music in different areas, especially bedrooms with no music devices. The use of music streaming services provided staff with a comprehensive music catalogue ensuring music was always appropriate and preferred by residents.

Some care roles have more flexibility in implementing PAMI-UK than other i.e., activity coordinators vs carers. However, it was felt that carers could easily implement PAMI-UK into their limited time schedule as the skills can be incorporated into other tasks in short increments.

"It takes a couple of seconds or minutes to sing to someone that might change their mood or encourage them to take their tablets. It's not something that's a long process that you've got to do. I think quite simple to fit in." CH01 CA Interview

Additionally, CA argued that the benefits outweighed the time requirements. PAMI-UK allowed staff to include meaningful activities and interactions into routines without additional time burden by incorporating the activities and interactions alongside physical tasks such as personal care.

"You're not going to do it like half eight in the morning when you got all your personal care to do and all that. But with PAMI, you can hopefully kind of change that and introduce it as you're working with your resident. You can actually do things during personal care. So, I think there's certainly ways you can fit it in day to day" CH02 CD Interview

## 5.3.4.6.2 Barriers

Despite finding PAMI-UK easier to implement than other interventions, at times staff still found it difficult to implement due to time restraints.

"You don't always get the chance to do it throughout the day" CH02 CC Reflective session 2

CC sometimes felt her attention was required on other responsibilities leaving no time during shifts for PAMI-UK. Additionally, some staff believed PAMI-UK required more time and effort compared to other music activities.

*"I think sometimes trying to find the right time, space, area and person-centre it, you have to like work it out... Whereas the Christmas [music] thing it was just a free for all" CH02 CD Reflective session 3* 

CD felt PAMI-UK required additional effort and planning compared to other music activities that sometimes start spontaneously. CD views were contrasting to those who found the intervention naturally and seamlessly fitted into their routine. CD suggested that finding the time might not be the barrier it was more an issue of finding the right time. "It's just finding the right time, not the time. Cause we always have time. It's finding the right time to do it." CH02 CD Reflective session 1 Additionally, although PAMI-UK skills can be incorporated into routines, attending

training requires additional time, CA, CH01's deputy manager, reported the challenges of scheduling training for multiple staff.

Staff mobility between different units and residents resulting in days where the participating resident had no PAMI-UK interactions. Staff spent more time on different units than usual owing to COVID-19 and unit-specific lockdowns. Staff shortage due to illness led to an increased workload for the remaining staff, reducing the already limited time. Additionally, sickness among participating staff led to residents experiencing days without PAMI-UK interactions. Although staff found using their phones a facilitator, some care homes had a no phones-on-shift policy, restricting staff ability to provide music.

## 5.3.4.6.3 Long-term Implementation

During the interviews, all staff responded positively to long-term implementation. CB responded before the facilitator even finished the question, as she was so sure of her answer.

# *"Sorry, I'm interrupting you there as I know that's a definite" CH01 CB Interview*

*"I think it's important. I don't think it should ever stop, whether I'm here or not." CH01 CB Interview* 

The benefits for staff and residents experienced led CA to believe all staff should be trained in PAMI-UK and used with all residents. Staff not only recognised PAMI-UK's long-term potential, but many also reported the wish to continue to use PAMI-UK post-study, with care homes making adaptations to incorporating PAMI-UK further.

## 5.3.4.7 Theme 7 Staff's Experience of Participating in the Study

Overall, staff were positive towards the study design and felt that the relationship with the researchers ensured the study ran smoothly and they felt comfortable.

"Both of you were so approachable and that on the reflective sessions if we did have a problem, I feel like I could have asked you anyway... or obviously,

## *RF (In-Reach Practitioner). So, I wouldn't hesitate if I wasn't sure on something." CH01 CA Interview*

Over the two months, staff became familiar with the researchers, developing a relationship that led to staff feeling comfortable asking questions and expressing their experiences openly. The fortnightly sessions ensured staff felt supported throughout the study and issues could be solved timely and efficiently.

Staff reported the addition of the In-Reach Practitioner valuable as it gave staff an inperson contact they could discuss issues with.

"It's nice to see a person, isn't it? I mean, the reflective meetings and stuff would be enough... If you couldn't get out there and someone couldn't come and do it... It's only someone dropping off documents... But it's just nice to see a person." CH02 CD Interview

Staff appreciated having an in-person contact as it provided a personal approach to the study.

Staff found that the requirement to document their experience provided an incentive to attempt skills regularly. Documentation led staff to spending time reflecting on the skills and residents' responses.

"We put pressure on ourselves, cause we felt that we had to have something to show you. We can talk. I can talk about a million examples but trying to write it down it's a mental block." CH02 CD Reflective session 3

CD's quote highlights that regular monitoring and documentation improved participants' compliance with the intervention. The use of different documentation ensures accessibility; for staff who struggled to write their experience could verbally articulate then during reflective sessions. Participants suggested that the diary pages could be more suitable by making the boxes larger, due to struggling to write indepth descriptions in the small boxes.

CA was a deputy manager who informed the researchers she had regular shifts providing caring responsibilities, making her eligible for the study. However, due to manager's sickness and other deputy manager responsibilities, CA could not commit sufficient time to the study resulting in her incorporating PAMI-UK significantly less than the other staff.

"It's been busy, and I've been stressed out. Because obviously, I'm taking part in this study, and I haven't been getting on very well with it because of my job role and that sort of thing. As RF (In-reach Practitioner) was trying to-... she said don't worry about it CA it's all, this is it all good for research and that sort of thing. I said well I suppose it would show that probably a deputy manager isn't quite fitting for this sort of research." CH01 CA Reflective session 3

CA's involvement in the study demonstrates the potential to train all care staff regardless of their job role. However, in terms of the study, management as participants may be unsuitable. Although involving management in the study ensured maintained staff motivation and enabled them to organise staff schedules to work with the study's logistics.

The study set-up consisted of all communications directed to the manager to ensure staff's personal emails were not required. However, having a gatekeeper caused some challenges for staff accessing information. CH02's manager was on sick leave for a large proportion of the study resulting in staff not receiving essential information and the researchers being unable to schedule study activities.

"I know all the emails that RF (In-Reach Practitioner) she was sending to (manager). But she has been off sick, so she's not been able to come and collect the paperwork until last week." CH02 CC Interview

Furthermore, the staff did not receive the teams' links from the manager until immediately before the start time. As a result, staff felt rushed and disorganised. CC suggested sending the team link to each participant's email.

Although all staff found the reflective sessions helpful, attendance rates were low. Only two staff members attended all three reflective sessions. Some participants missed sessions due to forgetting; they suggested sending reminders could improve attendance rates.

## 5.4 Discussion

#### 5.4.1 Key Findings

Staff demonstrated attempting all PAM-UKI skills and being able to determine which were most appropriate for their resident's needs. PAMI-UK improved residents' mood, memory, awareness of surroundings, verbal and non-verbal communication, and resistance to care behaviour. Whilst staff reported improvements in their mood, ability to manage challenging situations, communication, and confidence. The improvements led to the care home atmosphere being happier and more relaxed, with staff and residents interacting as equal partners. Task were completed quicker, smoother, and were more pleasant for staff and residents.

#### *5.4.2* Staff Learning

Participants recognised that despite years of caring experience, staff can continue to learn new interventions. However, Emilsson (2006) reported that for staff to engage in training, they must believe they can continue to learn new skills despite being qualified. Additionally, although they used music pre-PAMI-UK, the training provided knowledge on using music therapeutically, which is different to music listening. The care staff's reflection relates to McDermott et al's (2018) research which suggested a standardised staff-training tool was required to ensure music interventions, particularly music therapy skill-sharing, were implemented successfully and of high quality. Despite staff from one care home using PAMI-UK-like skills, such as cueing pre-PAMI-UK, they reported learning new ways to adapt their current practices and felt the intervention provided recognition of their abilities.

The training increased the staff's awareness of tailoring music to residents' preferences or using music from their era. When using appropriate and preferred music, staff received a more positive response from residents leading to more interactions that are meaningful. Paolantonio et al. (2021) highlighted the importance of relevant music for residents in care homes. During their study, residents reported being unable to relate to contemporary pop music as it was difficult to understand and conveyed meaning poorly.

#### 5.4.3 Using PAMI-UK

From the data collected, it can be inferred that the time and location of using PAMI-UK varies and relies on exploratory trialling to determine a suitable tailored PAMI-UK plan. Even once PAMI-UK has been tailored to a resident, responses may vary daily or throughout the day depending on dementia symptoms and external factors. In other communication interventions resident's responses varied making the interaction sometimes unsuccessful. Additionally, it took time before residents accepted the intervention (Söderlund et al., 2012).

Some staff felt PAMI-UK was inappropriate to use during illness and end-of-life care. Although PAMI-UK has not been researched in end-of-life care, there is extensive research highlighting the use of music in palliative and end-of-life care for a range of conditions, including dementia (Baroni, 2020; Black & Penrose-Thompson, 2012; Graham-Wisener et al., 2018; Tao, 2019; Johnston et al., 2022). As staff did not generally use PAMI-UK during resident illness, it is difficult to determine if PAMI-UK can be used in these circumstances. Whilst it remains to be seen, one possible hypothesis is that techniques that are more active may be unsuitable while residents are ill, but other techniques such as attunement and arousal regulation may remain beneficial during this period.

## 5.4.4 Training Delivery

This study highlights the plausibility of facilitating PAMI-UK training remotely. Staff could comprehend and successfully implement skills through online training and fortnightly monitoring sessions. Previous research suggests that staff prefer face-to-face training compared to self-directed studies or online modules (Surr et al., 2019). When having to convert PAMI-UK from a face-to-face training tool to a remote one owing to COVID-19 the researchers were conscious of these previous findings. They opted for live, interactive video conference training to create an environment closest to face-to-face whilst adhering to the COVID-19 government guidelines. Staff had a positive attitude towards the remote training, although some suggested virtual

training creates a different "vibe", is less personal, and would prefer in-person training if the situation allowed.

PAMI was developed to be flexible, allowing the intervention to be tailored and adapted to ensure person-centred care. At the same time, the training required structure to ensure the use of high-quality music skills. The original Danish researchers explored the paradoxical concept of developing a manual considered fixed and inflexible while remaining flexible and adaptable (Anderson-Ingstrup, 2020). Anderson-Ingstrup (2020) suggested a manual framework that maintains sufficient flexibility to allow for tailoring to each individual by guiding staff in using and choosing the appropriate elements, while also providing sufficient information for successful practical implementation. The UK version aimed to maintain this manual framework while also ensuring that staff could sufficiently comprehend and utilise the intervention. The outcomes of this study demonstrate the success of this approach, as each staff member was able to easily understand the skills and alter the intervention to their residents. Despite staff all possessing varying degrees of knowledge, skills, and experience, they found the training was accessible and targeted to their needs.

The changes to intervention structure were required to ensure that the intervention was culturally adapted for the intended stakeholders (UK care staff) in the intended setting (UK care homes). The feedback from staff demonstrates the trainings usability, suitability, and readability for UK staff suggesting that potentially the changing made from the PAMI-DK (Ridder et al, 2023) to PAMI-UK was sufficient. Overall, staff reported the manual being easy to use and well formatted, with the information readily available and accessible to return to after training. The fortnightly reflective sessions allowed staff to implement the skills into practice and receive guidance from the PAMI-UK music therapist on barriers and challenges, whilst maintaining motivating and incentivising staff to practise PAMI-UK for later discussion. Previous studies also highlight that interactive training elements and videos are effective, especially when they allow staff to translate theory into practice

(Surr et al., 2020, 2019; Rapaport et al., 2017). The reflective sessions acted as continuous mentoring and supervision, which has been identified as a facilitator for successful implementation (Surr et al., 2020; Rapaport et al., 2017).

#### 5.4.5 Barriers and Facilitators to Implementation

Previous research highlights the challenges of conducting research and implementing interventions in care homes due to time, resources, and finance (Surr et al., 2019, 2020; Luff et al., 2015). In this study, these challenges have been exacerbated due to COVID-19 (Ritchie et al., 2023).

PAMI-UK does not require additional specialist equipment; therefore, it does not require additional finances. Staff can use music devices already owned by the care homes. Staff found using music streaming services on mobile devices as the most accessible way to access music. However, the availability of music devices varies between care homes. Therefore, a lack of appropriate music devices and staff being unable, due to workplace regulations, or unwilling to use their phones could prevent successful PAMI-UK implementation and limit the intervention to care homes with sufficient finances. This barrier was also discussed in Foster et al. (2021).

Similar to previous care home research (Surr et al., 2019, 2020; Law and Ashworth, 2023; Groot Kormelinck et al., 2020), despite integrating PAMI-UK into current practices, time restrictions were highlighted as a potential barrier. However, because PAMI-UK can be integrated during other carer activities, limited time appeared to be less of a barrier in the PAMI-UK study compared to structured non-integrated interventions (Sung et al., 2011; Batt-Rawden & Srolien, 2019; Garrido et al., 2020). Staff and resident sickness were also highlighted as a potential barrier, as highlighted in previous research (von der Warth, 2021) especially during the pandemic. The study only consisted of a limited number of trained staff; however, outside of the study, delivering PAMI-UK as a care-home-wide intervention with all staff being trained could reduce some barriers and improve consistency across shifts.

Rapport et al. (2017) suggests that training all staff can promote learning and sustain practices.

To conduct this study, management support was vital, with two managers changing care home practices, including introducing more music into the care home and creating a music section in care plans. Their support ensured staff have sufficient time, space, and encouragement to implement the intervention. Similar advantages of managerial support are highlighted in other studies (Lawrence et al., 2012,2016; Surr et al., 2020). Training multiple staff from the same care home can cause scheduling issues, with management struggling to find a suitable time when staff were on shift without staff shortage. Similar to Melhuish et al.'s (2017) study, some staff attended reflective sessions and interviews during their days off, notably one night carer completed all elements off shift. The expectation of staff completing training on their day off can result in reduced motivation and increased drop-out rates (Surr et al., 2020).

# 5.4.6 PAMI-UK in Relation to Current Theory

PAMI-UK can be considered a form of Integrated Model of Music Care (IMMC), which integrates music elements into caring relationships, care tasks, personal care plans, and within care communities (Foster et al, 2021). The results suggest that staff implemented PAMI-UK into all these care areas. Typically, staff found it beneficial to incorporate PAMI-UK into personal care tasks, mealtimes, medication, personal transfer, and morning rounds. Staff observed a reduction in agitation, resistance to care behaviour, and improvements in mood and communication. MTC (MTC) (Götell et al. 2002, 2003a, 2003b, 2009, 2012; Hammar et al. 2011a, 2011b, 2011c 2010), another IMMC, explored using music during similar times and reported similar results. The difference between the two interventions is MTC consisted of caregivers singing while PAMI-UK consisted of various musical skills.

# 5.4.7 Covid's Impact on the Study and Implementing PAMI-UK

The study ran while care homes struggled to manage the COVID-19 pandemic, with COVID-19 guidelines restricting activities and interactions. All care homes

experienced a COVID-19 outbreak during the study leading to lockdowns either carehome-wide or unit-specific. During the study, staff and residents were sometimes separated on different units leading to limited interactions until the staff member returned. Some resident participants contracted COVID-19, leading to isolation with contact limited to essential care. During instances where residents were COVID-19 positive, it was noted by managerial staff that PAMI-UK could still be incorporated into essential care to ensure positive musical interactions continue when contact is restricted, ensuring residents' psychological, social, and emotional needs are met. PAMI-UK elements consist of using the voice and non-verbal communication, therefore, staff faces being visible is essential and this visibility was reduced when staff were wearing face masks. To compensate for the masks staff began exaggerating their facial features and became more conscious of using body language.

Ultimately, staff felt that PAMI-UK provided a positive opportunity during the pandemic. Reduced social interactions, anxiety, and the fear of COVID-19 led to many individuals withdrawing from the care home community resulting in deterioration in symptoms (Alzheimer's Society, 2020; Gordon et al., 2020; Velayudhan et al., 2020). However, staff felt that PAMI-UK offered an opportunity to improve interactions and slowly reduce social isolation.

#### 5.4.8 Changes to the PAMI-UK Intervention and Study Design

# 5.4.8.1 Changes to the Study Design

This study provided feedback on the manual and study's suitability and cultural appropriateness, enabling the researchers to make adaptations. Some staff experienced research anxiety, resulting in one participant withdrawing. To improve staff's anxiety the researchers developed a one-page summary providing more information about the facilitators, intervention, and study in a less formal format than the participant information sheets (Appendix 13). The diary entry boxes have been increased based on feedback to allow staff to write in-depth descriptions. Personal emails were not used to reduce the amount of personal information

collected; however, the Teams link and information were not always sent to staff from the managers in sufficient time. The use of personal emails will improve the ease of attending sessions and improve attendance rates, as staff will receive notifications reminding them about sessions. Researchers will also send an email reminder the day before scheduled sessions to improve attendance rates.

#### 5.4.8.2 Changes to the PAMI-UK Intervention

During the reflective sessions, staff discussed other music activities provided in the care home, which were seen as separate from PAMI-UK, therefore, taking time away from incorporating PAMI-UK skills. Additionally, staff found it challenging to use PAMI-UK with their participating resident while caring for non-participating residents. As a result, the researchers included a section in the manual and training discussing group music activities and the ability to incorporate PAMI-UK into current, pre-existing activities. Information on social interactions between residents was also added to the manual to discuss PAMI-UK's potential role in facilitating resident-resident interactions.

Resulting from staff's suggestions, blank pages for notetaking were added to the updated manual. During the reflective sessions, confusion over the different elements was discussed. The staff did refer to the manual to improve understanding; however, the length can make it challenging to locate the information quickly. A recap PAMI-UK sheet was created to allow staff to access essential PAMI-UK information quickly (Appendix 17).

Staff referred to the same limited number of PAMI-UK interactions, despite PAMI-UK being implemented for eight weeks. The lack of in-person observation made it difficult to determine whether staff only used PAMI-UK a handful of times or only documented the interactions they felt were worth noting. A reflective session prompt sheet was created to enable staff to create detailed written lived experience descriptions. Staff were expected to complete one a fortnight, which the researchers hoped would increase the number of different interactions discussed. As part of the

prompt sheet, staff set fortnightly goals which the facilitator returned to in the next session to see whether goals were met. The setting of goals aimed to make the intervention more person-centred and provide more guidance on practical implementation (Appendix 16).

# 5.4.9 Methodological Difficulties and Limitations

#### 5.4.9.1 Care Home and Participants Characteristics

All participating care homes belonged to the ENRICH program, an organisation that promotes research in care homes. Therefore, there is a potential sampling bias. The care homes were more likely to be interested in academic research and interventions resulting in more motivated staff and managers. The high level of managerial support demonstrated in the study may have resulted from managers being approached first to recruit the care home. Therefore, potentially only care homes where the manager was enthusiastic about the intervention and research participated. The recruitment method may result in the sample being unrepresentative of the general UK care home population. A small sample size and high dropout rate led to only five dyads completing the study, with all participants being female and British. Once again, the small sample size and participant characteristics does not represent the general population of UK residents and care staff.

# 5.4.9.2 Using the Same Researchers to Facilitate the Intervention, Interviews and Complete Data Analysis

The same two researchers facilitated the training, reflective sessions, interviews, and completed data analysis. Using the same two researchers could have led to a 'researcher effect' with preconceptions influencing each study stage. The two researchers were aware of their potential preconceptions and used reflective diaries. The results were discussed with the study PI, who had limited involvement in the other study elements to also reduce the chance of 'researcher effect'. Additionally, using the same researchers for all stages may have led to staff being more open about their experience as a relationship had been developed, as highlighted by one participant who was anxious to complete the interview. Previous research has also

highlighted that the familiarity of the interviewer may outweigh potential researcher effect as it could promote more enriched data (Hammar, 2011).

# 5.4.9.3 Delivering the Study Remotely

As all elements were completed remotely, the researchers were unable to observe staff implementing PAMI-UK. Therefore, it is difficult to determine whether staff incorporated PAMI-UK or general music activities in some scenarios. Additionally, staff were asked to document PAMI-UK interactions with one resident, however it became apparent during the reflective sessions that staff discussed multiple residents without distinguishing between them. Therefore, it is difficult to determine whether the results presented are from the participating resident.

#### 5.4.10 Future Research

Using the feedback from staff on the manual and training the researchers discussed as a team, changes that were required for the PAMI-UK tools and study design. A PAMI-UK manual version 2 was created in preparation for the manual evaluation study. The manual evaluation study aimed to explore the cultural appropriateness, suitability, usability, and readability of PAMI-UK version 2 taking into consideration the results from this study. The manual evaluation stage also planned to begin phase four of the cultural adaption framework by beginning to explore the feasibility of PAMI-UK and the impact of PAMIUK on staff and residents using quantitative outcome measures.

#### 5.4.11 Implications

This study builds on previous evidence for the benefits of music in care homes for residents with dementia. PAMI-UK is a staff-skill sharing music manual that provides staff with a range of musical skills traditionally reserved for music therapy, that have the potential to benefit residents, staff, and care homes. Due to finances and music therapists' limited availability only a selected number of UK care homes employ music therapists, therefore, a large proportion of UK care homes fail to benefit from obtaining specialist knowledge from music clinicians. There is limited music training available to staff and usually provides insufficient supervision to ensure high-quality

skills and successful implementation. PAMI-UK has the potential to provide a larger proportion of care homes with music training with regular monitoring which can improve staff and resident interactions. To our knowledge, PAMI-DK and PAMI-UK are the first manuals to provide a standardised manual to promote two-way attuned musical interactions in care homes. By incorporating PAMI-UK into current routines and tasks, the intervention does not require additional staff time or burden. The study demonstrates the plausibility of introducing music interventions into care homes despite limited carer's available time.

#### 5.4.12 Conclusion

This was a field-testing study to determine the suitability, usability, and readability of the PAMI-UK training tool to ensure its appropriateness for the intended setting of UK care homes. The study targeted the phase three of the FMAP (Hwang, 2009) and Barrer and Castro (2006) frameworks for culturally adapting interventions. Overall, staff found the manual and training useful, easy to follow, and suitable for care homes, but provided suggestions for making the intervention more suitable for the UK. The suggestions made aided the manual development process resulting in a PAMI-UK version 2 manual being produced. The PAMI-UK skills were incorporated into care staff's daily routines, mainly during care tasks such as personal care, medication time, and mealtimes. The staff saw improved residents' mood, notably reduced agitation, resistance to care behaviours, and improved communication and social engagement. Staff improvements were also observed, including in mood, awareness, and attunement with residents. Although the current study highlights positive potential benefits of implementing PAMI in UK care homes, this was the first study to explore PAMI-UK and PAMI delivered remotely; therefore, more research is required to further explore the effectiveness and benefits of PAMI-UK.

# 6. Manual Evaluation Study

# 6.1 Introduction

The manual-field testing results (Chapter 5) led to several amendments to the PAMI-UK manual and training to improve usability, readability, and suitability resulting in the development of PAMI-UK resources version 2. A second study was conducted to continue to explore the improved PAMI-UK manual to further determine usability and appropriateness. Due to the limited research on PAMI, this exploratory study was conducted to explore the study design and gain a preliminary understanding of PAMI-UK's impact on care home staff and residents. The data collected will determine sample sizes, data collection methodology, recruitment and retainment, and outcome measures for future studies. This study continues to explore phase three of the cultural adaptation frameworks while also beginning to explore phase four (described in chapter 3).

# 6.1.1 Aims

- To investigate the practical implementation of PAMI-UK in UK care homes
- To explore the feasibility, usability, acceptability and readability of the PAMI-UK manual and training tool within UK care homes
- To investigate PAMI-UK's impact on residents' musical engagement, mood, social engagement, communication, and quality of life
- To investigate PAMI-UK's impact on staff's dementia competence, mood, stress, burden, and communication

# 6.2 Method

An overall detailed methodology is presented in Chapter 4, the methodology below highlights the methodology specifically for the manual evaluation study.

# 6.2.1 Study Design

This was a mixed-method study consisting of repeated quantitative measures and qualitative data collection through interviews, session transcripts, diary entries, and questionnaires. The quantitative data aimed to collect preliminary data on the impact of PAMI-UK on staff and residents and explored the suitability of the outcome measures for future studies. The qualitative data aimed to build on the manual field-testing study to investigate further PAMI-UK's feasibility, usability, suitability, and readability to ensure cultural appropriate adaptation. Similar to the field-testing study, this study aimed to collect further data on using PAMI-UK in a real-life context to gain insight into implementing PAMI-UK in UK care homes. The data collected assisted with the final alterations of the PAMI-UK training tool to produce the PAMI-UK resources version 3.

# 6.2.2 Setting

The study ran between March and November 2022. The researchers aimed to recruit five care homes in Lincolnshire through the In-Reach pilot scheme who were invited to participate by the In-Reach practitioner. The care homes recruited were different to the care homes in study 1. All care homes had a CQC score of 'good' (Chapter 4 provides more details on the settings.).

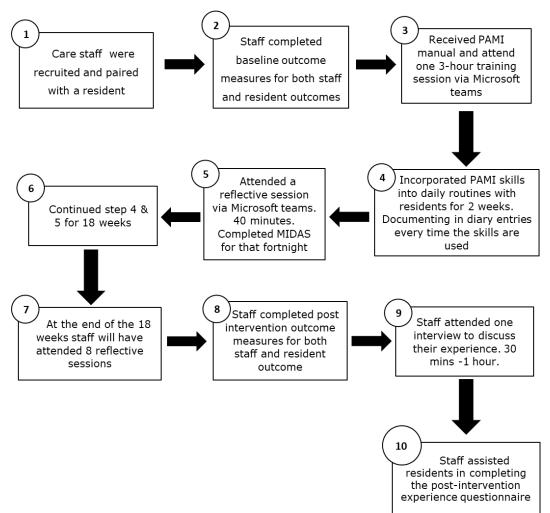
#### 6.2.3 Participants

The study aimed to recruit 25 residents with dementia and 25 care staff before pairing them together post-recruitment. The eligibility for both staff and residents were the same as the manual field-testing study (See 5.2.3 Participants in Chapter 5 for the eligibility criteria).

#### 6.2.4 Intervention

All staff participants were trained in the PAMI-UK interventions using the PAMI-UK resources version 2, which contained the adaptations recommended in the field-testing study (Intervention adaptations available in Chapter 5). Staff were required to attend a 3-hour group interactive webinar, which could be completed in one or two sessions. After the initial training, staff were expected to incorporate the skills regularly and consistently into their daily routines for 18 weeks. Staff attended around eight fortnightly 40-minute reflective sessions with other participating colleagues to reflect on their practices. The number of reflective sessions were selected based on previous feedback and the researcher predicted eight sessions would provide staff with sufficient time to explore all the PAMI-UK skills, gain sufficient supervision from the music therapist, and begin tailoring PAMI-UK to their specific resident (more information on the intervention is available in Chapters 3 and 4.)

# 6.2.5 Procedure



*Figure 6.1 A flow diagram presenting the procedure for staff participants in the manual evaluation study* 

Figure 6.1 presents the study procedure for the manual evaluation study for staff participants. The study ran for 20 weeks, with PAMI-UK being implemented for 18 weeks.

#### <u>Step 1</u>

Recruiting care homes, staff, and residents remained the same as in the field-testing study including care homes being recruited through the In-Reach scheme. Initially care homes were invited to join the study by RF. Managers from participating care homes were asked to introduce the study to their staff and residents who could express their interest to RF. For residents who lacked capacity, a consultee was appointed. (Chapter 4 provides more information on recruitment and consent). Once consented, care staff and residents were paired into dyads.

# <u>Step 2 & 3</u>

At the beginning of the study, staff received a paper PAMI-UK manual version 2, care staff and resident demographic questionnaires, a diary entry form, a dementia-friendly demographic questionnaire, and the DSRS (Clarke & Ewbank, 1996). Staff also received the baseline questionnaires, including the Music in Dementia Assessment Scale (MiDAS) (McDermott, 2014), Sense of Competence in Dementia Scale (SCIDS) (Schepers et al., 2012), QUALIDEM (Ettema et al, 2007) and Modified Nursing Care Assessment Scale (M-NCAS) (Kleinman et al, 2004), to complete before the training, minus the MiDAS, which was completed during the training. An additional eight MiDAS and eight reflective prompt sheets were included in the pack, which staff required for each reflective session. Care home managers completed a care home demographic questionnaire. Staff were asked to provide a personal email, which was used to access the Teams links. At the end of the training webinar, staff completed the first MiDAS.

# <u>Step 4, 5, 6</u>

After the training, staff implemented PAMI-UK, deciding when to use the skills at their discretion based on their resident's needs. Staff were expected to use the skills regularly and were asked to document their experience using the diary forms. Staff attended online fortnightly reflective sessions delivered by a music therapist. Reminder emails were sent to the care home and participants the day before a session. During the fortnight, staff were asked to consider one PAMI-UK interaction and write a lived experience description on the reflective prompt sheet. During the sessions, the facilitator explored the interactions with staff in detail. At the beginning of the session, the facilitators monitored the study procedure, including monitoring reports of distress and participants willingness to continue participation. At the end of the sessions, staff were asked to document at least one goal for the coming fortnight on the reflective prompt sheets and to complete the next MiDAS time-

point. Staff were expected to complete eight reflective sessions. If a reflective session had not been booked in, the researchers sent periodic emails encouraging staff to book their next reflective session. Staff were informed they could either complete the reflective sessions as a group or independently depending on the convenience of the care home. BS facilitated the reflective sessions up to mid-September 2022 when she went on maternity leave. The remaining sessions were planned to be facilitated by BW or OM. When BW facilitated the session, she was supported by OM, a music therapist, if any questions or concerns arise that required a music therapist's expertise. Only one reflective session was attended after BS left.

#### Step 8, 9 & 10

After 18 weeks, staff were invited to an online post-interview facilitated by BW. The post-intervention version of the outcome measures were sent, along with a post-intervention experience questionnaire to be completed by residents with sufficient communication ability. Care homes and staff members received a participation certificate and a summary of the study results.

#### 6.2.6 Ethics

Some amendments were made based on the manual field-testing results, which required ethical approval. Some of the amendments included giving the In-Reach Practitioner more responsibilities as she was able to attend the care homes more, created a one-page study summary to reduce anxiety, asking for staff's personal emails rather than the care home's email and changes to the recruitment numbers due to high dropout rates in the field-testing study. The amendments received ethical approval from the London - Harrow Research Ethics Committee in March 2022 (REC reference-21/LO/0283). (Chapter 4 provides more details on ethics.)

#### 6.2.7 Data Collection Methods

#### Qualitative Data

# 6.2.7.1 Diary Entries

Staff were asked to complete the diary form to document each PAMI-UK interaction. The diary entries provided data on the frequency of use to determine whether there was an optimal amount of time for using PAMI-UK and to explore the care staff's usage behaviour.

# 6.2.7.2 Residents Experience Questionnaire

The residents' experience questionnaire explores the resident's experience of PAMI-UK. As residents' dementia severity varied, the researchers were aware that not all residents could complete the questionnaire. Staff were informed to assist their resident with the questionnaire if residents could communicate their experience sufficiently. (More details available in Chapter 4)

# 6.2.7.3 Reflective Session Transcripts

The reflective sessions were informal and guided by the staff's experience and needs. Data collected consisted of issues with PAMI-UK, lived experience descriptions, and implementation of PAMI-UK. After the first session, which was used as a catch-up, the following three sessions focused on one of the PAMI-UK core elements. The reflective prompt sheets guided the remaining sessions.

# 6.2.7.4 Reflective Prompt Sheets

Staff were asked to complete one reflective prompt sheet a fortnight, documenting a lived experience description for one interaction. The lived experience description aimed to describe one interaction in-depth exploring the components of the interaction and the resident's reaction. The lived experience descriptions and goals on the sheet were used as a data collection method to explore the types of interactions occurring and residents' responses. The goals set were compared with later reflective session to determine if goals were achieved. The goal aimed to tailor the intervention to residents making it more person-centred.

#### 6.2.7.5 Staff Interviews

Each staff member completed a semi-structured 30-minute post- intervention interview online. BW facilitated the interviews by following a topic guide.

(More information on the qualitative data collection is available in Chapter 4)

#### Quantitative Data Collection

#### 6.2.7.6 Resident's Music Engagement

A modified MiDAS (McDermott et al., 2015) measured residents' music engagement. Typically, it is proxy-reported, completed by care staff and the music therapist before the start of music therapy and again post-session to examine changes during the session. In the PAMI-UK study, the MiDAS was still proxy-reported. However, it was completed only by care staff at nine time points at fortnightly intervals, first in the training and then at each reflective session. The measure uses Visual Analogue Scales (VAS) without anchor points, consisting of a 100mm line. Staff are asked to rate the individual based on their current stage of dementia; therefore, highest means the optimal level that the individual can achieve at that stage of their life. As the individual's dementia progresses, their optimal level will likely change. The MiDAS consists of five VAS: Interest, Response, Imitation, Involvement and Enjoyment, a checklist question on major reactions, and a comments question. Each scale is manually measured using a ruler to generate the score. MiDAS has a total maximum score of 500, with each VAS' maximum score being 100. The measure was selected as it collects observational data on music engagement using proxy-reporting methods, making it suitable for moderate to advance dementia participants. Studies investigating the psychometric properties of MiDAS reported high internal consistency, acceptable test-retest, acceptable concurrent validity, and high construct validity (McDermott et al., 2014a).

## 6.2.7.7 Resident's Quality of Life

QUALIDEM is a dementia-specific proxy-rating scale measuring the quality of life of individuals with dementia (Ettema et al., 2007). The scale has been designed to be suitable to use with participants in care homes. The QUALIDEM was completed preand post-intervention with 18 weeks between time points. The multidimensional

scale contains 37 items, using a four-point scoring from 0-3, across nine homogeneous subscales. The subscale scores are calculated by adding the item scores. The higher the subscale score, the better quality of life on that domain. An overall score can be calculated, but the author advises against this.

QUALIDEM was selected because it measures emotional and social domains, the care relationship, and coping with the nursing home environment, a domain not investigated in other scares. QUALIDEM has moderate inter-rater reliability, moderate internal structure, and high convergent, discriminate, and concurrent validity (Ettema et al., 2007; Arons et al., 2018).

#### 6.2.7.8 Staff Dementia Competence

SCIDS investigates staff dementia competence and its relation to care behaviour and the resident's quality of life (Schepers et al., 2012). SCIDS is a professional caregiver's self-report measure comprising of 17 items using a four-point scale, categorised into four subscales: professionalism, sustaining personhood, building relationships and care challenges. Overall scores range from 17-68, with a higher score indicating a higher sense of competence. The measure was completed before and after PAMI-UK. The SCIDS has been reported to have good internal consistency and substantial or moderate test-retest reliability.

# 6.2.7.9 Staff Burden

M-NCAS measured staff burden pre- and post-PAMI-UK. The M-NCAS measures behaviour, staff's perception of the meaningfulness of residents' lives and residents' gratefulness for care. The M-NCAS was adapted from the Nursing Care Assessment Scale to include more items to provide a greater comprehension of staff burden (Kleinman et al., 2004). The M-NCAS is a self-reporting staff measure consisting of 32 items. Each item had two domains; one explores the occurrence and intensity of behaviours, and the other explores the staff's difficulty coping with the behaviour. Each domain is scored on a four-point Likert scale. A lower score on both domains indicates a lower staff burden. The M-NCAS has been reported to have excellent/good internal consistency, reliability, and moderate construct validity.

#### 6.2.7.10 Returning of Documents

After the challenges of obtaining completed documents in the manual field testing it was decided that the In-Reach Practitioner would attend the care homes regularly to collect completed study documents. During each reflective session staff were reminded to complete the measures for that specific time point. At the end of the interview staff were asked to complete all final documents and ensure they were available at the care home for RF to collect. RF contacted each care home after the end of the study to organise a convenient time to collect the remaining study documents. RF sent periodic emails to each care home enquiring about the return of the study documents. Once collected, RF returned completed documents to the research team via post. The researchers regularly monitored the returning of documents providing each care home with a list of missing documents. The first care home completed the study in mid-September 2022 and the last care home completed the study in early-November 2022. The research team attempted to obtain returned documents until March 2023.

#### 6.2.8 Analysis

#### 6.2.8.1 Quantitative Data

The demographic, DSRS, MiDAS, SCIDS, QUALIDEM and M-NACS data were imported into SPSS statistics (IBM Corp, 2021), where means and SDs were generated. The researchers planned to use multiple imputations to deal with missing data. Multiple imputations were selected to deal with missingness as it computes multiple plausible values, reducing the likelihood of bias by accounting for the uncertainty of the missing data (Sterne et al., 2009). If individuals were missing more than 50% of data on a single outcome measure, they would be excluded from the analysis. Initially, Little's (1988) missing completely at random test would be conducted to determine whether data was missing completely at random, if it was, multiple imputation could be used. Missing completely at random assumes that the missingness is independent of the observed and unobserved data (Mack et al., 2018). Multiple imputations would not be used for MiDAS, as the score is the individual's optimal level at that particular stage of dementia therefore each individual optimal level would be

different. Instead, the mean of the other items at that time point would be used to deal with missing data.

The researchers planned to conduct a paired t-test for the SCIDS, QUALIDEM and M-NCAS, to investigate the change in means pre- and post-PAMI-UK. Before conducting the t-tests, the data would be tested to assess the parametric assumptions, including testing for normal distribution. If the data did not meet the assumptions, a Wilcoxon signed-rank test would be conducted. The researchers planned to conduct a repeated ANOVA for the nine MiDAS time points. Before conducting the ANOVA, assumption tests would be conducted. A Friedman's test would be conducted if the data was not normally distributed. Post hoc tests would be conducted if the ANOVA reported a significant change between time points.

Due to the small return rate of the questionnaires and high levels of missing data, the researchers consulted with a statistician, and it was determined that multiple imputations and intended statistics could not be conducted on the data set. Instead, the median imputation was used to deal with missing data. If questionnaires were missing more than 50% of the data, the individuals were excluded from the analysis. The mean for each questionnaire for all participants was conducted for pre- and post-PAMI-UK, and the researchers explored the changes in means. Wilcoxon signedrank tests and Friedman tests were conducted to gain a greater understanding of outcomes that future research may want to investigate with a larger sample size. Non-parametric tests were used as the sample size was too small to validate the normal distribution.

#### 6.2.8.2 Qualitative Data

The audio recordings from the reflective sessions and interviews were transcribed using the University of Nottingham Automatic Transcribing service before being reviewed by BW for accuracy. A second reviewer (BS) up to the point of her maternity leave reviewed transcripts; BW only reviewed the remaining transcripts. The finalised transcripts were imported into NVIVO. The diary entries, reflective session transcripts, interviews, residents' experience questionnaires, and reflective

prompt sheets were analysed using thematic analysis (More information on the qualitative analysis in Chapter 4). BW generated the codes and considered themes representing the data. The transcripts were then reviewed by OM and considerer in relation to the themes generated by BW. BW and OM discussed the themes, refined, and renamed themes to represent the data appropriately. Each staff member is reported as C and a letter and residents are reported as R and the corresponding letter as their carer.

When the resident experience questionnaires were returned, it seemed they reported the staff's experience not the resident's experience. Therefore, the resident experience questionnaires were removed from the results.

#### 6.3 Results

The researchers recruited four of the five care homes initially planned between April 2022- July 2022, with 39 out of 45 (86.6%) participants recruited. Twenty staff members and 19 residents created 19 dyads. In Care Home 3, one staff member dropped out before the training and was replaced by a different staff member; the resident remained the same. Ten dyads (52.6%) remained in the study for the entire duration. Staff dropout reasons included resigning from their job, inability to commit the required time, and personal circumstances. Three staff members did not attend training and were considered to have dropped out when they did not respond to contact. Only two of the seven staff members who dropped out after the training returned the baseline measures. The residents whose staff members dropped out were withdrawn. Four further staff members were considered a loss to follow up as they failed to return their post-intervention questionnaires. One of the four staff members also did not return their baseline measures.

Across the care homes, 17 of the 31 (54.8%) reflective sessions were attended. One care home had only seven sessions due to the scheduling of training. Reasons for missing sessions included annual leave, staff sickness, COVID-19, CQC inspection, care home emergencies, shift patterns, residents' days out, and broken internet. Care Home 2's staff were the only participants to complete all required reflective sessions. *Table 6.1* presents dropout rates and attendance rates.

Care Home code	Participant number (dropout rates)	Training attendance number	Number of reflective sessions attended
Care Home 1 (CH01)	5 (2)	5	4 (50%)
Care Home 2 (CH02)	5 (3)	4	7 (only 7 sessions fitted into the 18 weeks) (100%)
Care Home 3 (CH03)	8 (3)	7	3 (only first reflective session attended by all staff) (37.5%)
Care Home 4 (CH04)	2 (2)	1	4 (dropped out after 5 sessions)

Table 6.1 Staff participant numbers, dropout rates and reflective session attendance

## 6.3.1 Care Home and Participations Demographic Characteristics

Care home characteristics (*Table 6.2*) were only returned for three care homes. All three homes were classed as residential, with one specialising in dementia care. Two care homes were privately owned, while the third was charity owned.

*Table 6.2 care home demographics, including the number of residents and staff: resident ratio* 

Care Home code	Number of residents	Staff: resident ratio
CH01		
СН02	60	1:4
СН03	43	1:7
СН04	24	1:6 am or 1:8 pm

Nine of the 17 staff members who completed the training returned their staff demographic questionnaire (*Table 6.3*). Eight staff members were female, and one (5.9%) male aged between 22 and 65. Eight staff members had the nationality of either British or English and one had a German nationality. Time employed at the participating care home ranged from six months to 15 years. Time spent in dementia care overall ranged from eight months to 15 years. Some staff had only worked at the participating care home, while others had worked in multiple homes.

	N	Mean	SD
Age	9	46.22	14.42
Years at the care home	9	3.28	4.48
Years in Dementia care	9	5.96	4.38

Table 6.3 Staff member demographic characteristics including age, years at participating care home and years in dementia care

Demographic questionnaires were returned for nine of the 16 (56.2%) residents whose staff attended the training (*Table 6.4*). One participant did not report the time living at the care home or fully complete the DSRS scale. From the data returned, eight participants were female, and one male aged between 61-96. Eight participants were British or English, and one was Belgian. Time living in the care home ranged from six months to three years. Participants had moderate to severe dementia based on the DSRS (19-51).

	Ν	Mean	SD
Age	9	83.78	13.07
Years at the care home	8	1.61	.89
DSRS	8	38.63	5.37

Table 6.4 Resident characteristics including age, years at the care home and total score on the Dementia Severity Rating Scale.

# 6.3.2 Data Analysis of Diary Entries and Reflective Session Prompts

### 6.3.2.1 Results From the Reflective Prompt Sheets

Ten participants returned reflective prompts, although the number of prompts completed varied. Some interactions had been discussed in the reflective sessions, while others were new. The sheets documented both positive and negative outcomes. When negative outcomes occurred, staff were not discouraged by the result; instead, many documented plans to attempt the interaction again.

The reflective prompts reiterate the resident outcomes presented in the reflective sessions and interviews but also document new outcomes. Staff reported PAMI-UK

improving residents' decision-making with them being able to choose what music they wanted which in turn increased music engagement. The reflective sessions documented improvements in food consumption at mealtimes; however, the prompt sheet additionally reported the improvement in positive weight gain owing to increased food consumption. Staff became more conscious of their interaction elements, resulting in more time spent interacting meaningfully. They learnt to allow interactions to develop naturally, which were directed by the residents even if this resulted in moving away from PAMI-UK. Accepting PAMI-UK took time, with residents slowly reacting more positively to skills as the study progressed.

The Connecting element was a prominent skill documented, with staff interacting through physical touch, eye contact and dancing. When observing the prompt sheets in consecutive order, development in skills and relationships was apparent. Staff used a combination of PAM-UKI skills within the same interaction.

During the reflective sessions, some participants reported little to no resident engagement and reactions. However, their prompt sheets demonstrated a range of interactions where the resident was engaged and responding. These reactions were subtler than other resident outcomes, which may be why staff did not report them.

Staff who missed reflective sessions continued to complete the prompt sheets allowing the research team to monitor progress. Despite the limited supervision, the staff who only attended one reflective session demonstrated their understanding and ability to incorporate PAMI-UK. When reviewing the prompt sheet aims in the context of the other prompt sheets and reflective sessions, the aims can be observed being explored in subsequent weeks.

PAMI-UK goals set by staff included:

- Demonstrate to other staff the PAMI-UK skills suitable for a particular resident so they can be used will the staff members on annual leave.
  - 238

- Spend time interacting with a resident before starting a task.
- Use framing to wake residents in the morning.
- Encourage the resident to engage in group activities.
- Encourage interactions between residents.

# 6.3.2.2 Results From the Diary Entries

Four diary entries were returned, with two participants documenting 12 entries and one documenting nine entries over the 18 weeks. The fourth participant documented 11 entries but only remained in the study for five weeks. It is difficult to determine whether staff documented all PAMI-UK interactions that occurred. As the diary entries were not documented as intended, frequency and descriptive statistics were not conducted. The diary entries demonstrated the same interactions to the reflective sessions, prompt sheets and interviews.

Staff documented using 'Balancing' and 'Connecting' prominently; however, other PAMI-UK skills were used. Noticeable changes in residents during PAMI-UK interactions compared to Pre-PAMI-UK was observed, including residents being calmer and more content when listening to music, which continued into the rest of the residents' day. Some staff developed residents' personalised playlists containing appropriate music for arousal regulation which could be used for anxiety or agitation. When using music to cue, residents created associations between the music and task, orientated residents, reducing confusion and anxiety. Staff and residents displayed using music and non-verbal communication to connect, resulting in increased smiling and laughter. CN and RN at CH04 used mirroring to aid interactions, CN observed RN's behaviours and mirrored them to alter the interactions to their ability. Residents displayed increased verbal communication, although this generally consisted of single words.

### 6.3.3 Quantitative Analysis

There was no significant difference between staff who dropped out and those that remained in the study in age (U=3.50, P=.15), time at the care home (U=13.0, p=.30),

the number of residents in the care home (U=7.50, P=1.0), SCIDS total (U=9.0, P=.52), M-NCAS behaviour occurrence total (U=9.0, p=1.0), M-NCAS staff coping score (U=8.0, p=.51) or M-NCAS pre-stress levels (U=3.50, p=.65). There was a significant difference in the total time in dementia care (U=17.0, p=.04) with the dropout group having a mean of 10.33 years (SD = 4.16) compared to the remain group's mean of 3.78 years (SD = 2.56). Although there was no significant difference between most of the variables, only 5 staff members who dropped out returned their documents and an additional 5 dropped out but did not return their documents. There could be a difference between withdrawals who returned their documents and those that did not.

There was no significant difference between withdrawn resident whose documents were returned and those that remained in the study in age (U=7.0, P=1.0), Number of residents in the care home (U=10.0, p=.51), time at the care home (U=3.0, p=.83), DSRS score (U=7.0, p=.74), Pre- QUALIDEM total (U= 4.0, p=.50) and Pre- MiDAS total (U=9.0, p=.32). Additionally, there was no difference in those that withdrew and those that remained on the pre-QUALIDEM subscales or pre-MiDAS subscales.

#### 6.3.3.1 SCIDS

Eleven staff members returned at least one SCIDS questionnaire. Ten participants returned their pre-SCIDS questionnaire. Two of the ten had missing data, with one participant missing one question (5.88%), and the other six questions (35.29%). Seven participants returned their post-SCIDS questionnaire. Two of the seven had missing data, with one participant missing two questions (11.76%), and the other five questions (29.41%). Six out of the 11 staff members returned both the pre-and post-SCIDS. From the six participants, only one questionnaire was missing data, with five questions missing (29.41%). There was no significant difference in the pre-SCIDS score between those that only completed the pre-questionnaire and those that completed both pre- and post-questionnaires.

The mean SCIDS score pre-PAMI-UK was 57.50 (SD- 3.33) and 60.50 (SD 4.72) post-PAMI-UK, an improvement in scores from pre- to post-. A Wilcoxon signed-rank test indicated a significant difference in the median score between the pre-SCIDS total score (59.0) and Post score (62.0) Z=20.0, P=.04.

#### 6.3.3.2 M-NCAS

Ten staff members returned at least one M-NCAS questionnaire. Nine participants returned their pre-M-NCAS. Two questionnaires were each missing one behaviour occurrence question (0.31%). Seven pre-questionnaires were missing staff coping questions, with 59 questions missing ranging from missing one (0.31%) question to 30 questions (93.75%). The questionnaire missing 93.75% was not included in the final analysis. Three participants did not complete the two stress level questionnaires. Seven participants returned their post-M-NCAS questionnaire. Two questionnaires were missing staff coping data, each missing one question (0.31%). One participant missed one behaviour occurrence question (0.31%).

Six of the ten participants completed both the pre-and post-M-NCAS, of which five questionnaires were missing data. Twenty-two staff coping level questions were missing across the pre-questionnaires. Two people were missing one question (3.13%), one person was missing two questions (6.25%), one person was missing three questions (9.38%), and one participant was missing 15 questions (46.88%). Three participants missed the two stress level questions. Two participants each missed one question (3.13%) from the post-questionnaire.

The mean M-NCAS behaviour occurrence score pre-PAMI-UK was 65.83 (SD- 11.79) and post-PAMI-UK 65 (SD- 7.87). The mean score difference from pre to post was .83 (SD-9.22). The mean M-NCAS staff coping score pre-PAMI-UK was 60.33 (SD-22.64) and 58.17 (SD- 17.03) post-PAMI-UK. The mean score difference from pre to post was -2.33 (SD-11.02). A Wilcoxon signed-rank test indicated no significant difference in the Behaviour occurrence medians pre- (68.5) and post-PAMI-UK (64.50) Z=4.0,

P=7.15. There was no significant difference between the Staff coping scores medians for pre (63.0) and post (66.5) Z=9.0, P=.686.

Three participants answered both the stress question Pre-PAMI-UK, with two participants reported not feeling stressed pre-PAMI-UK, whilst one reported feeling stressed. The three staff members had a mean stress score of 3.67 (SD- 1.53). All participants answered the post stress question, three individuals reported feeling stressed, and three individuals reported not feeling stressed. The mean stress score was 2.33 (SD- 1.03). For the three staff that completed both the pre and post stress questions, there was a mean score difference from pre to post of -2.33 (SD-58).

# 6.3.3.3 QUALIDEM

Nine staff members returned at least one QUALIDEM questionnaire for their resident, with all returning their pre-questionnaire. One of the pre-questionnaires had been returned blank. Of the remaining questionnaires, 28 questions were missing from six questionnaires. The number of missing data ranged from one question (2.5%) to 16 questions (40%). Seven participants returned their post-questionnaire. From the post-questionnaires, two were missing data, with one missing five (12.5%) questions and the other 2 (3%) questions. Six participants returned both their pre- and post-questionnaires. Out of the individuals who returned both questionnaires, four pre-questionnaires were missing data from two individuals, with one missing one question (2.5%), one missing two questions (3%), one missing six questions (15%) and one missing 16 questions (40%).

The mean QUALIDEM total score pre-PAMI-UK was 81.33 (SD-11.72), and post-PAMI-UK was 78.67 (SD-14.40). The mean care relationship score pre-PAMI-UK was 15.67 (SD-2.34), and the mean post-PAMI-UK was 16.67 (SD-3.56). The positive affect mean score was 14.17 (SD- 2.04) pre-PAMI-UK and 14.67 (SD-2.73) post-PAMI-UK. The Pre-PAMI-UK negative affect mean score was 5.83 (SD-1.72) and 5.33 (SD-1.21) post-PAMI-UK. The mean restless tense behaviour score pre-PAMI-UK was 4.17 (SD-2.14) and 10.33 (2.50) post-PAMI-UK. All participants' restless tense behaviour scores

increased from pre to post, with the score increasing between three and seven points, suggesting that staff perceived residents as having more restless tense behaviour post-PAMI-UK. Positive self-image had a mean score of 7.33 (SD-1.86) pre-PAMI-UK and 5.33 (SD-1.37) post-PAMI-UK. Pre-PAMI-UK residents' mean social relation score was 10.67 (SD- 1.21), which changed to a mean of 8.83 (SD-1.33) post-PAMI-UK. The pre-PAMI-UK social isolation mean was 6.17 (SD-1.94), which changed to a mean of 5.17 (SD-2.32) post-PAMI-UK. The feeling at home mean pre-PAMI-UK 10.0 (SD- 1.67), and post-PAMI-UK it was 8.67 (SD- 1.86). Having something-to-do had a mean score of .67 (SD-.52) pre-PAMI-UK and .67 (1.21) post-PAMI-UK.

A Wilcoxon signed-rank test indicated a significant difference between the pre-QUALIDEM restless tense behaviour median score (5.0) and post median score (10.0) Z=21.0, P=.03. There was no difference for any of the other QUALIDEM subscales (Table 6.5) Table 6.5 The QUALIDEM Wilcoxon signed-rank test. The table presents the median score for each subscale for pre- and post-questionnaires, the Z score, and the P value. \*Significant P values

Subscale	Median Pre- PAMI-UK	Median Post-PAMI- UK	Z score	P value
Care relationship	15.5	18.0	16.0	.24
Positive affect subscale	14.5	15.5	10.0	.50
Negative affect	5.5	5.33	11.0	.33
Restless tense behaviour	5.0	10.0	21.0	.03*
Positive self- image	8.0	5.5	1.5	.10
Social relation	6.5	9.0	.00	.07
Social Isolation	6.5	4.0	.00	.18
Feeling at home	10.0	9.0	16.5	.21
Having something to do	1.0	.00	9.0	.74

# 6.3.3.4 MiDAS

Nine participants returned at least two MiDAS sheets, but the majority completed four or more. One participant returned all their MiDAS questionnaires uncompleted. Only one participant had a VAS question missing data, with them missing two questions. Twenty-six major reaction questions were missing data across the nine participants. Five participants returned all eight MiDAS. There was no significant difference between the scores at the different time-point for any of the MiDAS subscales or overall total. (Table 6.6).

MiDAS subscale	Chi-Square	P Value	
Interest	11.18	.19	
Response	5.0	.76	
Initiation	10.14	.26	
Involvement	9.42	.31	
Enjoyment	6.55	.59	
Total	9.70	.28	

Table 6.6 Friedman test scores for each MiDAS subscale and total MiDAS score at the 8 timepoints

# 6.3.4 Qualitative Analysis

Eight themes and 20 subthemes emerged from the thematic analysis (Table 6.7).

vera	rching theme	Subthemes
1.	Staff identified PAMI-UK skills and key components Residents' behaviour changes as a result of PAMI-UK	<ul> <li>Staff demonstrating using PAMI- UK skills</li> <li>Principles &amp; mechanisms</li> <li>When to use PAMI-UK</li> </ul>
3.	Staff benefits and behaviour changes	<ul><li>Staff benefits</li><li>Increased awareness</li></ul>
4.	Increased interactions and forms of expression	<ul><li>Interactions</li><li>Forms of expression</li><li>Relationships</li></ul>
5.	PAMI-UK's impact on the care home, including non- participating residents and staff	<ul> <li>Non-participant residents</li> <li>Other staff</li> <li>Care home atmosphere and changes to practice</li> </ul>
6.	PAMI-UK interactions at resulted in unexpected of negative responses	
7.	Staff views on PAMI-UK and intervention components	<ul> <li>Staff's views on the manual</li> <li>Staff's view on the interactive webinar</li> <li>Staff's views on the reflective session</li> <li>Learning abilities</li> <li>The online format</li> </ul>
8.	Implementation of PAMI-UK within a care setting	<ul> <li>Barriers</li> <li>Facilitators</li> <li>Implementation</li> <li>Practical consideration</li> </ul>

Table 6.7 themes and subthemes generated from the reflective session and interview

# 6.3.4.1 Theme 1 Staff Identified PAMI-UK Skills and Key Components

# 6.3.4.1.1 Staff Demonstrating Using PAMI-UK Skills

All staff demonstrated exploring the different PAMI-UK skills and were able to determine which skills were appropriate for long-term implementation with their resident based on the resident's reactions. Staff showed good comprehension by being able to adapt the skills to fit with different residents or scenarios.

### PAMI-UK Element 1: The Voice

Staff developed a greater awareness of their voice, with them becoming more aware of how parameters such as tone and volume could influence residents' interactions. Making minor changes could catch a resident's attention or prevent agitation depending on their residents' mood and arousal states.

"It depends on the tone of voice, how you use it to get them motivated a bit more. Like with RA she's already quite up there with her mood so sometimes you need to be a bit more calmer, a bit more relaxed and other times you need to raise the tone of voice a bit, so she understands that you are there." CH01 CA Reflective session 1

The quote highlights links between The Voice and Balancing; sometimes, staff needed to employ either a calming or energetic tone to decrease or increase arousal, respectively.

Although the staff had good communication skills pre-PAMI-UK; the training made them more conscious, enabling them to adjust when their skills slipped due to stress or tiredness.

"I talked to them calmly all the time already anyway. But do you know when you're really tired and like you don't realise your tone of voice, I listen more to that."- CH01 CC interview

### PAMI-UK Element 2: Framing

For many, cueing became a natural morning addition to wake residents and orient them to personal care.

"We have used it to say wake her up, or so I'll do it sort of while I'm taking her through personal care. So, we will sing some sort of songs that she knows that we hope she can join in, and sometimes it's just trying to keep her calm and allowing personal care" CH01 CA reflective session 1

CA discovered that morning cueing helped orientate, reducing the chances of high arousal, resulting in improved task efficiency with RA becoming more cooperative. By the end of the training, RA developed associations with both songs or visual cues for several tasks.

"We get our big green meds trolley out at teatime, and she will come and stand at the side of me... she keeps poking me as much to say come on where mine... so she is getting time orientated, certain things are triggering her" CH01 CA reflective session 4

Although PAMI-UK does not explicitly train staff in using visual cues, since starting PAMI-UK CA had noticed RA becoming orientated to times with her creating both visual and musical cues leading to reduced BPSD's and increased awareness. CH also used music to orientate residents to the time of day, although she reported using songs that associated with the tasks such as *"Morning has broken" (CO3 CH interview)* during morning care.

All staff members developed an increased awareness of the sound environment, but the ability to make changes varied between care homes, scenarios, and times of day. In CH01, there was a correlation between the success of PAMI-UK and residents' bedroom location.

"RO's room is towards the end of the corridor, where it's quiet and so does RA. Whereas RD, there's a lot going on... so sort of the ones that seem to again benefit more on the quieter ends of the corridor in their rooms, so they can't hear all the sounds going on" CH01 CA reflective session

Staff observed that residents benefiting the most from PAMI-UK were situated in quieter areas, they suggested that a poorer sound environment could have adversely affected the implementation of the other PAMI-UK skills. Few changes could be made due to the necessity of daily cleaning; instead, staff began scheduling meaningful musical activities in the afternoon when the sound environment improved. Staff became aware of their behaviours, a factor they could control, that negatively contributed to the sound environment.

"I'm a lot more quieter like putting the cutlery away, cause that annoys me when people are loud with it. But... I didn't realise I was being loud with it" CH01 CC Interview

# PAMI-UK Element 3: Balancing

Balancing was incorporated frequently into routines, often alongside other PAMI-UK skills and was used as either a preventative or reactive method. Incorporating Balancing techniques during stressful and agitation-inducing situations such as personal care was considered beneficial.

"We have a nearly blind, nearly deaf resident who obviously, when you touch them, they thrash out. When a carer was taking this resident for a shower, she just asked me to assist... And I asked her if she would mind if I tried PAMI.... As soon as she touched the clothes, the arms are out... So, I just started very very gently singing her name in her ear. And it calmed, but nothing that you would really think was special. Well, this lady was a missionary. So, I started singing... 'All things bright and beautiful' to her... It was like she'd been hypnotised. She sat there. she didn't move. She didn't trash. We did the whole procedure... and I just kept singing to her all the time. She was completely relaxed." CH03 CI reflective session

CI initially gained the resident's attention by using her name and a gentle voice, making the identity of the carer known creating security and predictability. Singing a meaningful song that matched the resident's arousal level reduced the resident's anxiety enabling the staff to complete personal care.

For one resident, using over-ear headphones blocked external stimuli preventing overstimulation and high arousal.

"They've realised that when they take her anywhere. If they take her to A&E, they take her there with her earphones on in the hospital... and that helped." CH01 CA Reflective session 1

Playing CA's balancing playlist through headphones enabled her to maintain a balanced arousal in agitation-induced situations both inside and outside the care home.

Staff used the Balancing skill Grounding prior to a resident interaction to centre themselves removing stress, anxiety, and frustration.

"Was using PAMI for myself also to relax myself... you've been through a lot during the day, and I was just planning. I was just doing my reports... So, I decided to play the music I like... I didn't play music for them. I was playing it for me just to cool myself down." CH03 CE Reflective session 4

CE regularly mentioned experiencing stress, PAMI-UK helped her recognise high stress levels and aided with maintaining a balanced arousal state. The additional energy and time required for PAMI-UK interactions resulted in staff needing the right frame of mind and arousal state otherwise, it could negatively influence the interaction.

"You know singing is from the- the mind and from the spirit... the way she shouted, 'help', you get agitated yourself. You get annoyed yourself, so the music cannot flow naturally... I think I have to calm myself down. I have that at the back of my mind" CH02 CE Reflective session 4

For staff to work effectively to improve residents' behaviours and well-being, they first need to work on their well-being.

# PAMI-UK Element 4: Connecting

Staff connected with non-verbal residents through non-verbal communication and music.

"I've not really tried it with this particular resident, but since the meeting and this particular resident, they don't normally communicate much. But they sort of held their hand, and they started singing the song to me about being a lovely lady... their wife came in. And then he sang a song to her as well. And I've never seen him do that." CH02 CP Reflective session 1

Despite the resident rarely communicating verbally, he used the song to express himself. However, at the time, CP had not attempted PAMI-UK with the resident.

Staff reported that interactions with participating staff resulted in less agitation and more cooperation in task compared to non-participating staff.

"He's okay with me. Then when I am entering his room, I say 'good morning. How are you darling? Are you alright?' Then he said, 'Yeah, I'm alright'... It's okay but sometimes he is very aggressive 'uh get out from room- my room'... Then I am entering that room he said 'ohhh sorry sorry sorry it's you. I'm sorry I thought any other one is coming to my room'" CH02 CG Reflective session 4

The resident may have been less agitated and more apologetic for his behaviour with CG as she took the time to connect with him before performing care tasks. CI also connected with RI personally before attempting care tasks.

"You've gotta connect with him, you've got 'hello, should we go upstairs and see if we can find your favourite CDs.'... Put that on in the bedroom, get his hands have a little bit of a dance and then get down to the practicalities and then he's more settled" CH03 RI Interview.

By connecting first, RI had a more balanced arousal state and was more cooperative during personal care.

Both CA and CE demonstrated using Validation and Holding during the study. "I've tried to find ways to instead of just sort of- I think a lot of people say have a cup of tea and biscuits rather than try and sort of get them to interact or trying to calm them down if they're anxious." CH01 CA Interview

CA acknowledged the residents' anxiety and distress as a potential form of communication when other communications are impaired. Rather than low-effort solutions, giving residents time and space to work through their emotions reduced agitation and anxiety more effectively. When considering the reasoning behind 'problematic behaviours, ' she used PAMI-UK to communicate and comfort residents.

"Some people that just think... it's behavioural. While other people think it's a crying out for help. While I personally think it's a crying out for help, there's something going on that she doesn't understand, and she can't communicate to you." CH01 CA Reflective session 1

RA was experiencing distress and uncertainty at the beginning of the study, with staff unable to determine the cause. Some staff interpreted the resident's behaviour as purely behavioural, with no intention behind the act; however, CA interpreted it as a form of communication when RA was scared and confused.

CE regularly discussed a resident who constantly shouted 'help' irrespective of staff assistance. During one interaction, CE dedicated time to sit with the resident to comfort her and acknowledge that her emotions were valid. "There is this resident that is always shouting 'Help, Help, Help' So that day I just thought, can we just do something... and so I sang this song with her... 'Lean on me when you are not strong, I'll be your friend'... So, I was singing for her... Then later she... put her head on my shoulder. Then she started crying. So, I told her '.... I'm not singing for you to cry I'm singing for you to know that yes, we are here to help you. So, what do you want' and then she got emotional. She- she started telling me what she could not remember." CH02 CE reflective session 5

CE reported that no previous strategies had effectively reduced the resident's distress and anxiety. However, when singing to express that she was present and acknowledged the resident's emotions, the resident could express herself, reducing her distress.

Staff developed an increased awareness and ability to interact and respond to residents' emotions, demonstrating attunement.

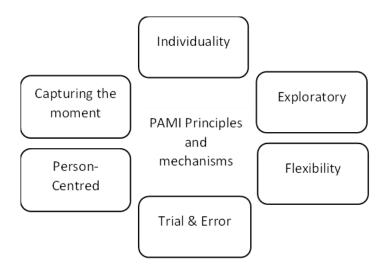
"She talks constantly, she very vocal. It's nothing that makes any sense... You really got to pick up on how she says certain things to gauge what she's

getting at sort of after a while " CH01 CD Interview

RD had limited sensical verbal language. Instead, CS interpreted her tone to determine her needs. CD highlighted that attunement required time to learn about the resident and to develop a connection.

## 6.3.4.1.2 Principles and Mechanisms of PAMI-UK

Staff identified fundamental PAMI-UK principles and mechanisms that correlated to the principles defined during the manual development stage (Figure 6.2).



*Figure 6.2 Principles identified by care staff, which correlate to the principle defined during the manual development stage.* 

Each resident had different needs and impairments, which influenced the implementation of PAMI-UK; therefore, the most appropriate skills varied between residents. Some differences resulted from the individual's dementia, while others from arose individuality between people. A significant proportion of the study involved staff experimenting with skills to develop a tailored personalised plan.

" I've tried some of the different methods with RC and some of them have worked, some haven't, but that's just because that's her dementia" CH01 CC Interview

Staff were confident experimenting with skills before selecting the most appropriate ones to continue using. PAMI-UK enabled staff to learn new information about residents by being exploratory.

"I've been finding out myself because RC's husband does spend a lot of time with RC, but he didn't know... she liked, Frank Sinatra until I told him... I put it on one day on the off chance and they were sat on the balcony, and I was sat singing to her" CH02 CC Reflective session 1

CC and other staff members discovered that residents' music preferences can differ from those suggested by their families. Some families could not provide a preferred music list; the exploratory nature of PAMI-UK allowed staff to experiment with different music.

"With RD... about a few times this week just sat with my phone and gone through various music"- CH01 CD reflective session 1

The staff reported that the intervention requires them to be exploratory to be able alter the skills used in response to the current moment and residents' responses.

"Although I had the manual, I didn't use it a lot. I just went with where we were in the- in the moment because I think if I was forever going right will this work am I doing this and I have got the manual." CH03 CH Interview

CH highlighted both the need for exploration but also the trial-and-error nature of PAMI-UK. Staff needed to attempt different skills to determine which were the most appropriate for their resident. The learning process was continuous, with staff regularly making adaptations.

" It doesn't take much to distract her, so it was like keeping her- keeping her engaged. And it was finding out slowly what worked and what didn't work" CH01 CD interview

CD struggled to gain and maintain RD's attention; therefore, it required trial-anderror until he discovered skills that captured her attention. Once staff discovered suitable PAMI-UK skills, determining factors influencing outcomes was also a trialand-error.

Staff recognised that residents' personalities and preferences pre-diagnosis can also influence PAMI-UK, with the residents having different music preferences similar to themselves.

"I think also it depends on the resident because some residents like- like us, don't particularly like music in the morning. You know it's a bit like us as individuals... It's just a bit of personal choice" CH03 CJ Reflective session 3

CJ acknowledged the person has preferences irrespective of their dementia. To ensure PAMI-UK remained person-centred, staff continuously assessed residents' reactions and engagement, adapting appropriately as the resident's dementia progressed.

Staff were more consciously aware of the different staff-resident interactions enabling them to recognise potential opportunities for more meaningful interactions. Staff felt they needed to *"capture the moment"* rather than preplanning interaction, especially for less responsive or vocal residents. "There wasn't a massive reaction, but when there was, it was golden because, as I say she wasn't- she not generally reactive or – or overly verbal resident. " CH03 CH Interview

RH displayed little engagement in interactions; therefore, when CH recognised small moments for interactions, she was proactive in using the opportunity to connect.

Staff were extremely busy during their shift; therefore, capturing available moments to interact and develop relationships was vital.

"It not possible just to say we're going to do it with this because so little time in the big scheme of things. it's like those moments are really precious because that person has connected with you; you've connected with that person. And so, it's again, it's building that relationship on the journey" CH03 CJ Reflective session 3

Staff recognised that although some interactions are short, they are still important as that residents has chosen to connect with them and cumulatively improve their relationship.

Staff acknowledged the individuality of individuals and therefore concluded that an unsuccessful attempt at a skill did not necessarily indicate a failure of PAMI-UK but rather suggested that the skill was not well-suited for the specific resident.

"That didn't really work..., but again that's just- that's purely individual. I can-I can see how it would work." CH01 CD Interview

### 6.3.4.1.3 When to Use PAMI-UK

PAMI-UK is designed to be flexible in its delivery, with staff encouraged to use the intervention in relation to residents' needs. However, some patterns arose of potential beneficial periods to implement PAMI-UK.

Incorporating Cueing or Balancing into personal care reduced agitation and increased awareness and resident cooperation. Finishing a nursery rhyme diverted one resident's concentration away from the task and her resistance towards concentrating on the song, which allowed staff to complete the task.

"she's very contrary, whatever you say... Why would I do that for you?... So, we started singing 'Mary, Mary, quite contrary, how does your garden grow' and she actually finished it for us. So now every time she gets a bit agitated

like that, that's what we do, and she finishes the actual nursery rhymes... She does what you ask her to do, but- but there's no like verbal from her. Well, because obviously, she's concentrating on finishing the nursery rhyme rather than why would I do this?" CH03 CK Reflective session 3

Using PAMI-UK during personal care made completing tasks quicker, smoother, and less stressful. For some dyads, personal care was the only time the resident accepted music; therefore, these interactions became a time when music was used to connect and help the task go smoothly.

"When I sit with him, and I'm giving him personal care... If suddenly he recognises the song, he'll sing along to that. But if I try to engage him in singing just in general, he doesn't... He didn't want me to do his nails, but once we started, you know, humming and singing and doing all of that, he was distracted by the music, so he was then able to relax." CH03 CH Interview
For both RK and CH music during personal care distracted them providing an opportunity for staff to complete the task.

Mealtimes were highlighted as a valuable time to incorporate PAMI-UK to support residents. In CH01, turning the television off and playing music instead, cued residents to the time. As the study progressed, residents of varying dementia severity would stand up at the cue. During mealtimes, music was played to remove distractions, making it easier for residents to focus on their food.

"They focus more with music than they do with the telly. They tend to eat better with music." CH01 CA Interview

The television created a sensory overload making it challenging to focus, by removing the television and introducing music improved focus resulting in improved food consumption and independent eating.

"RA seems to have got her appetite a bit better and- and is eating far better now. Whether it is the singing sort of 'food glorious food' to her or whether it's just 'cause she's just got her appetite back" CH01 CA Reflective session 4

CA could not confirm if the improvements resulted from singing food-related songs, but she was happy to continue if there was a chance that the songs were beneficial.

Some residents' dementia progressed during the study, moving them onto end-oflife care. The connecting element became vital to bring comfort and reiterate the importance of the residents.

"He was not able to talk any more. But when I entered, and he feel my presence... I just sang the song to make him know that, yes we love him, and he will forever be in our hearts. Then he looked at me, and I-I-I-I connected with the emotion we- I know we are both- have that connection at that moment." CH02 CE Interview

The interactions created comfort, for both the resident and staff member, with CR expressing that he was loved and not alone. Although RE was unable to communicate verbally, the interaction was not observed as one-sided. They connected through non-verbal communication, such as eye contact. When using PAMI-UK in end-of-life care, staff felt a sense of happiness for being able to make small positive changes to their final days, ensuring the resident was not alone.

Using music during personal transfers was observed to reduce agitation and increase cooperation.

"Even singing like 'follow the yellow brick road' and sort of she sort of paces more, jigs sort of thing" CH01 CA Reflective session

Using the same song created security and predictability by orientating residents to the next step. Additionally, an upbeat song gave residents more energy to complete the task. One participant was described as *"flowing down the corridor" (CH02 CH reflective session 1)*.

Staff reported that music helped one individual with Parkinson's disease to walk at a more natural pace by aligning their movement to the beat. Pre-PAMI-UK staff used a 123 waltz beat which seemed to work. However, there were more consistent results when the PAMI-UK music therapist suggested a 1234 pattern because it encouraged a more natural walking response.

"So I am now like 'Up 12 34' instead of '123 123'... It makes him smile and then he starts counting '12 34' so that been helpful" CH03 CK Interview

### 6.3.4.2 Theme 2 Residents' Behaviour Changes Resulting From PAMI-UK

Staff reported residents "*Enjoying life a little bit more*" (*CH01 CA Interview*) due to PAMI-UK. Residents displayed a change in mood with an increase in happiness, calmness and enjoyment observed through increased smiling, laughter, and playing.

"Literally everybody is happy" CH01 CA Reflective session 2 "Brightened their day a little bit when it happened" CH03 CK interview

RC's husband noticed the change in her mood, leading to the resident being more like her old self.

"When she first came here, RC's husband was a little bit scared. He was scared to put her here and kind- kind of upsetting.... me and RC dancing on that and it really made him happy like he's- she's more of her old self" CH01 CC Interview

PAMI-UK has reduced some of RC's BPSDs, making her personality more apparent. Her husband was initially concerned about her entering care; however, since seeing staff use PAMI-UK and the benefits, he was happier.

RH's ability to recognise people improved throughout the study.

" Probably me just reading into it, started to recognise me if I went in- in the sense of Ohh 'cause I'd put the music on, and we'd- we'd sway and sing along. So, she did sort of acknowledge that it was me, if you like, with more smiling and things" CH03 CH Interview

RH began recognising CH more, leading to increased reactions and happiness when they were around.

Extreme stiffness and tension during personal care were common due to residents' anxiety and agitation, making tasks more challenging.

"She's normally very calm, very placid, and she hasn't got mobility of her legs.... One morning she was chatting to her stuffed cat, and she was getting quite agitated, it was like, 'I'm going to thrash you' ... and she was very tense in her body. So, I just put on some Elvis Presley music... and I just started swaying and humming and that kind of thing. The next thing I know, she's joining in, singing the song... her whole body relaxed so that we were able to actually do personal care" CH03 CK reflective session 3 Staff encouraged residents to engage with the music before starting the task to reduce agitation and tension, making the task easier and more pleasant for both parties.

Across the care homes, staff reported an increase in residents' participation in both interactions and activities. Residents who were generally isolated or uninterested in care home activities engaged with the music.

"I asked if they both wanted to join in, and they both declined, and so I continued with the activity, but I put music on in the background, and as she walked past where we was doing it, she noticed the music that was on and saw everyone reaction to that and it kind of encouraged them joining in with the others. And I could see what kind of genre of music she liked." CH01 CB Reflective session 1

The introduction of music caught the residents' attention, who previously declined participation in the activity leading to them joining in. The interaction enabled CB to discover the residents' music preferences which she could use to increase participation in the future.

Levels of engagement varied based on dementia severity, but overall, residents engaged more and spent less time sleeping or experiencing apathy.

"The getting the resident to engage... it doesn't have to be all singing and dancing, just tapping on, tapping a tune on the- on the side and then you know joining in that oh we have a gentleman who walked around whistling all the time now or clicking, and that's his way of you know making a tune, and we were playing name that tune earlier" CH03 CK Interview.

Staff consciously worked to discover the most appropriate and successful interaction techniques based on residents' different abilities. CK recognised when residents attempted to interact and responded appropriately, ensuring the slightest cues were recognised and interactions were maintained.

### 6.3.4.3 Theme 3 Staff Benefits and Behaviour Change

## 6.3.4.3.1 Staff Benefits

The training provided CE with confidence and more self-belief to use the skills that she felt she possessed.

"PAMI brings out the confidence in me. Yeah, it brought out what is in me" CH02 CE Interview

Additionally, the intervention increased the staff's confidence in their role by providing additional skills to manage challenging situations.

PAMI-UK reduced staff stress by providing them with the skills to acknowledge and manage it.

"You know this job sometime- It's very, very sometimes you yourself you get agitated but the training at least it is a good training it shows me how to be calm and stuff like that" CH02 CE Interview

Having the skills to reflect on the situation and her emotions allowed CE to reset before interacting with residents, reducing her stress, and preventing it potentially negatively impact residents. Overall, staff reported feeling calmer and happier during their workday.

"The staff actually feel a bit calmer with it all in that respect" CH03 CK reflective sessions

Staff efforts of incorporating PAMI-UK, was acknowledged by both management and CQC inspectors.

" It's making us to stand out among our other colleagues" CH02 CE Interview.

*"Last week, the CQC came in there, they also happy that all residents are dancing with us. Uh dancing and playing with us and singing with us." CH02 CG Reflective session 2* 

The PAMI-UK training made the staff stand out from non-participating staff. In CH02, the staff's effort resulted in them being appointed temporary activity coordinators when the previous coordinator resigned.

## 6.3.4.3.2 Increased Awareness

Increased staff awareness resulted in resident cues and communication being noticed and acknowledged by staff. When an unexpected response occurred during an interaction, staff reviewed factors that could negatively influence the interaction allowing for adaptions to be made.

"I have been more aware of sort of what's going on and how many residents have been around and what activities have been doing to sort of try and see was there a pattern or anything" CH04 CN Reflective session 2 "The reason why I came across the 'aquarium' (A music collection based on fish) because there was something that did go wrong... It was a case of I had like a karaoke on YouTube, so it's got lyrics and the song playing. But it wasn't necessarily a positive sort of interaction that I was getting, nobody seemed to be interested with it, so that was why I decided to change" CH04 CN reflective session 2

PAMI-UK increased CN's awareness of residents' responses, instead of continuing an activity despite a lack of engagement she made changes accordingly to responses.

Daily fluctuation in dementia symptoms resulted in varying degrees of success with the same PAMI-UK skill; therefore, staff's awareness of residents' mood and behaviour changes were essential to determine the most appropriate skill for each interaction.

"It depends on their mood. You know sometimes you may use what you used yesterday, and you were trying to use it today, may not work. So, you just look at what they want at that at that particular moment, then you try." CH02 CE Reflective session 2

CE became more aware and attuned to her resident's needs leading to her recognising daily changes in mood and dementia symptoms, allowing her to adapt to the interactions.

# 6.3.4.4 Theme 4 Increased Interactions and Forms of Expression

## 6.3.4.4.1 Interactions

PAMI-UK's primary aim to create two-way attuned interactions was achieved by all four care homes. As the study progressed, RA became more interactive with other residents.

"She is slowly starting to go up to people... and holding hands and being more susceptible to their mood as well. When someone is upset, and she walks past them, she will sort of go and sort of touch them" CH01 CA Reflective session 4

Incorporating music into RA's routine increased her awareness of her surroundings, enabling her to interact with other residents. She could interpret residents' moods and emotions, resulting in her comforting upset residents through handholding and touch. PAMI-UK provided staff with the opportunity to share their life history and culture. CG, who had moved from India, regularly shared her culture with staff and residents by incorporating her language and culture into interactions.

" Then we started dancing, playing the Indian song. Then CG was teaching me how to dance with the- with the song" CH02 CE Session 5

During the interaction, CG taught CE Indian dancing, which aided the staff in connecting with the resident and each other. The dancing intrigued other residents who attempted to copy the dance. One another occasion CE used her language to connect with a resident.

"One resident is um um in his room always uh, he's bedridden-... His eyes always closed... one time I and my colleague went to personal care.... 'Shall you cooperate with us' He told me, 'No go away from here' then I sing a song in our language that in Malayalam music. Then he opened his eyes and asked me, 'what language are you- are you using?' Uh, then I told him 'I'm Indian, I'm using Malayalam.... and he responded with the same err the same like that word... then he told me 'What is mara' then I told 'Mara means rain'... that the first time he responded with the smiling face." CH02 CG Reflective session 3

The resident was isolated and challenging to interact with due to being closed off. Initially, CG sang to encourage the resident to engage in personal care; however, it led to them connecting through a language important to the staff member. The interaction was the first time he opened his eyes and smiled during interactions.

CG taught staff and residents about her culture through songs and words and in return she learnt more about English songs from residents. This teaching and learning between residents and staff assisted in developing meaningful relationships. Residents teaching staff was also observed in CH03.

"I actually got taught the jitterbug by one of the residents... She actually stood up and showed us how to do it with the frame, and she said no, you're not doing it right. You're- you're pounding your legs down. You need to, you need to swing your feet... In the end, there was about. 5 carers and about 3 residents, and we all learned the jitterbug from her." CH03 CJ Reflective session 3 The interaction enables the resident to be an equal partner, with the interaction providing the resident with a sense of purpose and connected her to her life history.

CH03's staff reported offering a range of high-quality beneficial music activities pre-PAMI-UK. However, staff developed a greater understanding of active and passive music after the training. For some residents, additional support from staff was required for them to engage in music and interactions.

" a lot of them just because they're in the same room as a music therapist, doing actions and going around the room...like with him, he was just sat there, and really not aware of what was happening in the room. But then it was like a light switched on. As soon as I started doing the actions in front of him... it made me really like him. Because before, and not saying that you know I didn't like him, but he did- he wasn't something that I was attracted... There's no connection... So, I see him in a completely different light because I saw him smiling, and he was enjoying it... but as soon as you stopped interacting with him, he didn't do it anymore... he didn't- didn't have the skills to to keep doing it... So just, even- so- so- even we a home that has got music therapy once a month. However, if- if we're not encouraging everybody to engage in it, there it's not beneficial" CH03 CJ Reflective session 1

The resident regularly attended music sessions without engaging, as previously staff had not directly interacted with him. Once provided with the additional support, the resident could engage, leading to CJ viewing them differently and strengthening their relationship.

Staff in CH03 increased their 1-to-1 interactions, with them being able to recognise when 1-to-1 was more beneficial for a resident compared to group activities.

"I think I'm more aware of when residents might need a little more 1-to-1 andand umm might sort of benefit from you just sitting there and maybe singing with them or humming with them or tapping out a tune with them." CH03 CK Interview

CK increased her awareness of the different types of interactions, recognising which was most suitable for a resident at a given time. CK's interactions did not require verbal communication for her to connect with her resident; singing, humming, or even being silent but together were used to interact.

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The musical interactions provided staff with opportunities to learn more about old and new residents, enabling better person-centred care delivery.

"She was a new resident... We are listening to music. Some are even telling me their past when we are listening to the music. Then I stood up, and I held her hand, and she started dancing. You know someone that doesn't talk, someone that is always keeping to herself. Someone that doesn't- that doesn't see anybody... I was shocked when she was dancing, and she was singing along with the music. So I will have to say yes, I was able to know that yes she likes music even if she's sitting alone... I was able to know that she can dance... I was happy at least the first person to detect that" CH02 CE reflective session 2

CE discovered new resident information through music reminiscing, which built on the residents' life history which could be used to improve their personalised care. Additionally, the music aided CE in interacting with a new resident, who was generally isolated. Learning that the resident like singing and dancing enabled staff to introduce this into the resident's care.

### 6.3.4.4.2 *Forms of Expression*

PAMI-UK encouraged staff to use other communication forms than verbal to enable residents to continue communicating and connecting with others. Despite losing the ability to articulate words, residents utilized variations in tone and rhythm to communicate through song.

"There was one lady started singing along... It was only La La La, but she hit every note perfectly, and this is a lady that sort of doesn't really communicate very well" CH01 CD Interview

The resident could process the song's musical parameters and adapt her sounds to match; the change was noticed by CD, who used the song to communicate with her.

When highly agitated, or anxious staff using physical touch, such as cuddling, and handholding created a sense of security, calmed the resident, and provided comfort. Two staff members held residents in their arms, which was compared to similar actions to soothing a baby.

" She ended up on the floor for about an hour and a half, and I was holding her like a little baby, and I just literally had her head in my arms whispering to her using a calming voice" CH01 CA Reflective session 1 The relationship between staff and residents was vital to create the security and trust needed to provide comfort. During the study, RA was experiencing unexplained distress; while trying to manage and understand the behaviour change, physical touch, closeness and adapting the voice reduced RA's distress and helped to complete tasks.

Residents used physical touch to show empathy or love during interactions, such as holding upset residents' hands or cuddling with a staff member allowing them to connect with the individual.

"She gets upset she loves the cuddles... take your hand and give you a kiss" CH01 CD Reflective session 4

CD struggled to implement many PAMI-UK skills due to RD's attention impairment; however, physical touch was an effective communication form for her.

For RA, PAMI-UK aided the improvement of verbal language, though she was the only resident to display improved verbal language.

"For like two hours, she was like dudu dudu. She doesn't really speak, but then she did it high-pitched and quite tuneful. I was laughing afterwards as though she was trying to sing, so there was a definite change in it... she was talking to me this morning, and I was just offering her banana she was actually trying to say different words this time" CH01 CA Reflective session 2

Pre-PAMI-UK RA had limited speech; however, she demonstrated signs of verbal language through changes in tone and pitch. When using words, there were signs of intention behind words and sounds, with them becoming more salient and relevant to the situation.

### 6.3.4.4.3 Relationships

Years of caring for the residents had resulted in relationships Pre-PAMI-UK; however, staff reported these existing relationships strengthened. Staff demonstrated their love for their residents and their emotional investment in the resident's care.

" I used to interact with her really well before anyway, but since being on the course with her... she's like my little best friend" CH01 CC Interview

"I think they are changing a lot of things, we are giving- I think we are giving a lot of love, lots of care" CH02 CG Interview

Creating a more person-centred relationship resulted in residents being less aggressive and more cooperative with participating staff compare to nonparticipating staff.

# 6.3.4.5 Theme 5 PAMI-UK Impact on the Care Home Including Non-Participating Residents and Staff

The PAMI-UK intervention had a broader impact on the care home, staff, and residents beyond those directly participating in the study.

## 6.3.4.5.1 Non-Participating Residents

CH03 perceived documenting only one resident as a missed opportunity for the researchers to capture more outcomes from PAMI-UK interactions. CH03 participants did not stick to only using the skills with the participating resident if an opportunity arose where the resident could benefit from a PAMI-UK interaction staff took the opportunity.

"I had so many really good interactions using music with other residents that I couldn't put down... They were missed opportunities for you to get some really amazing feedback... we didn't just stick to our one resident.... if there was an opportunity there to use and to calm a situation, then we just did, we did got 'oh no we can't- we're only using it on this with this resident'" CH03 CH Interview

The care home created a missed opportunity document to record PAMI-UK interactions with non-participating residents with similar results to the participating residents being reported. The intervention was reported as inclusive for all residents due to the skills being suitable for different dementia stages.

When staff used PAMI-UK in communal areas, many non-participating residents were interested in the music and interactions.

"A few things I tried in the communal areas, if RD wasn't into It, there were other residents that sort of joined in, and they sort of they- they all seemed to enjoy what was going on" CH01 CD Interview Outside of personal care, many PAMI-UK skills were used in communal areas resulting in other residents engaging with the skills or activities. Even when working with a specific resident, the music could unintentionally affect the surrounding residents.

"The other residents that are passing they came especially when we are dancing the Indian dance, so there are some residents that came they joined us... at that moment it's it's was fun" CH02 CG Reflective session 4

The interaction initially started as a 1-to-1 to regulate a resident's arousal; however, when surrounding residents heard the music, they joined, resulting in all the residents engaging together.

Overall non-participating residents reacted positively, however, some residents disliked music, so staff had to consider when and where to introduce the intervention.

"We only got one lady that's negative but she's she has a few behaviour issues... I was talking to her daughter about it, and she's- she's been like that all her life even before dementia started." CH01 CA Interview

The resident's daughter said that she disliked music pre-diagnosis. Staff had to learn to manage conflicting individualities to ensure that all residents' needs were considered in communal areas.

## 6.3.4.5.2 Other Staff

Non-participating staff were interested in the intervention once observing it in practice. In CH03, when non-participants observed PAMI-UK's positive outcomes, they asked participants to assist with challenging situations.

"Nobody has been negative towards us.... One or two have come up and said, 'can you just come and help us with so and so and see if it can calm them down a bit'." CH03 CI Interview

Staff were happy to assist and in many cases the inclusion of PAMI-UK enabled staff to manage the situation better, making a more pleasant time for the nonparticipating staff member.

PAMI-UK was well received by non-participating staff in CH02 and CH03; however, in CH01, the non-participating staff made incorporating PAMI-UK challenging. Some

staff members had preconceptions of the intervention without attending the training or observing the outcomes.

"There a stigma around some staff thinking this is not going to work at all. 'Playing some stupid music isn't going to help, and using a calm voice, well I already use a calm voice, and it doesn't help'... well they don't understand that some of them have gotten into that mindset" CH01 CC Reflective session 4

CH02 staff encouraged non-participating staff to use skills tailored to the resident to maintain consistency and improve the ease of care for all staff. However, some were reluctant to change, preferring to stick to their current practices.

When agency staff covered sick leave, incorporating PAMI-UK became more challenging.

"I work quite a lot on my floor agency workers... they don't really understand what's actually going on... I did tell one of them off because of the way with one of the umm residents because he knew full well she had dementia, and he did not handle it effectively umm, and he wasn't using a calm voice with her" CH01 CC Reflective session 4

### 6.3.4.5.3 Care Home Atmosphere and Changes to Practices

Staff increased the frequency of music playing throughout the care home; with them instinctively playing music in silent areas or during periods of inactivity. Staff believed it was more beneficial for residents than meaningless television watching. When music was used in communal areas, there was an overall effect on the care home atmosphere, with both staff and residents being happier and more engaged with the music and each other.

In CH01, PAMI-UK resulted in the senior carer reassessing the daily routine. PAMI-UK aided the implementation of a new system that aimed to complete morning care before lunch, leaving available time in the afternoon for meaningful activities and interactions.

" I've been trying a whole new system. Interact with the personal care and getting it done to where is it always seemed to be tailing off, and we're still doing it till 2:00 o'clock in the afternoon... I was trying to do it so we could sort of like got all the personal care done before morning and before dinner time, so then we have all afternoon to do something... to try and interact music wise, exercise wise or anything" CH01 CA Interview

# 6.3.4.6 Theme 6 PAMI-UK Interactions that Resulted in Unexpected or Negative Resident Outcomes

On occasions, outcomes to PAMI-UK interactions were unexpected or considered negative. Some residents only displayed subtle changes after PAMI-UK, which their staff expressed disappointment towards the lack of outcomes.

"Maybe sort of I ought to have picked a different resident... I thought I might see more of an improvement but more sort of going forward... I feel it's been quite limited... I suppose looking at the that previous sort of cases and things how alive people have become with the music... but how it got to that I suppose it might have been small steps" CH04 CN Reflective session 5

RN had interacted positively with CN, but she had expected considerable changes to occur in every interaction, whereas, in reality, she had observed sporadic and minor reactions. CN was an activity coordinator; therefore, her engagement differed from carers. On some occasions, RN had been sleeping or sleepy, resulting in CN not using the skills for several days. Additionally, CN did not finish the study due to leaving her job; therefore, only had several weeks to compare.

CN and CH reported selecting the 'wrong resident' for the study due to minimal interactions to document.

"My resident is very chilled and enjoys music but isn't very expressive. So, I found that quite difficult, although when she was expressive, it was really, really good, nice to see... just sort of mosey along so I found that when I found it difficult to sort of use a lot of the with the techniques" CH03 CH Interview

Although CH reported her resident displaying minimal reactions to the PAMI-UK techniques, throughout the study, CH documented multiple interactions with positive resident outcomes. RH did not require PAMI-UK skills such as balancing, but the connecting element was vital for the normally inexpressive resident.

In some cases, the area of care most challenging for residents was where the PAMI-UK skills evoked negative outcomes.

"There's no point in putting on music during personal care for RC... she doesn't respond to it because she's so high aroused. She confused so much, but just put music on, and it confuses her more as there more noise in the background" CH01 CC Reflective session 1

Personal care was highlighted as the area where RC required additional support; however, using music during this period increased agitation and confusion. Although PAMI-UK generally evoked negative outcomes for RC during personal care, the skills did occasionally evoked positive outcomes.

Residents' outcomes could be episodic with the same skills producing different outcomes on different occasions.

" First, she was smiling, and she was cooperating... I tried... it on Saturday she wasn't even looking at me at all, so I guess maybe it's a mood or anything" CH02 CE Reflective session 2

Staff believed the unpredictable responses were potentially due to external factors, including mood and dementia symptoms.

"It's been hit and miss because, obviously, she's different every day. She never the same every day" CH01 CC Interview

The daily fluctuation of dementia symptoms resulted in residents' reactions varying depending on the resident's impairments and abilities at the given moment. The uncertainty of responses did not deter staff from continuing to use PAMI-UK with the resident. As residents' dementia progressed their impairments and abilities altered, and some skills no longer became accessible to the resident.

"We have one resident... who, at the beginning, I gave my amazing example of a I sang to, is now deaf and blind, and she's gone really quickly, and she can't bear touch we have a terrible problem" CH03 CI Interview

The resident who had been partially blind and deaf at the start of the study was completely blind and deaf by the end, resulting in the previous techniques being ineffective. Staff found it challenging to interact with the resident; as auditory and visual cues were no longer suitable, and the resident disliked physical touch. For one resident, PAMI-UK consistently evoked a negative response.

"They're very very very umm, anti-personal care and they get very verbal and very rude. So, I have tried PAMI with this particular person. It's gone down like a lead balloon... If you make any noise, I mean even silence, it's screaming and shouting, 'why you not talking to me... If you are talking 'will you shut up, you know it's like you can't do anything right for doing wrong" CH03 CK Reflective session 5

The resident was reported to enjoyed music at other times except for during personal care. CK felt the loss of independence resulted in the high agitation, which she could not reduce using PAMI-UK despite attempting multiple skills. However, at the end of the study, she aimed to continue using music with the resident to determine if the challenging situation could be resolved.

Some PAMI-UK elements rely on the voice; when English was a second language, staff experienced negative responses from some residents due to preconceptions.

"Talking to some residents is quite difficult because they tell you they don't understand what you're saying... they tell you they can't understand the way we speak because we are foreigners .... We can't speak like them; our intonation is different... With this one... when you say something, she's saying something else. We try to repeat... demonstrate using the body language... but the other one... I am always trying to avoid him. I'm always trying not to talk to him... he talks to me in a bad manner" CH02 CE Reflective session 3

Interacting with residents who viewed staff as different due to nationality was an additional hurdle to manage. CE attempted to use skills that relied on non-verbal communication instead of verbal to reduce resident resistance. However, with one resident, she found no solution to manage the challenging situation.

## 6.3.4.7 Theme 7 Staff's View on PAMI-UK and the Intervention Elements

Overall, staff enjoyed the study and the intervention as they valued learning an extra tool that could assist with dementia care.

"I think that it taught me another skill to use, and any skills that you, anyone can give you working with dementia is fantastic. "CH03 CK interview

CK felt that all staff would benefit from the PAMI-UK training to equip them with an extra tool that could make caring for residents easier. She appreciated the researchers for allowing her care home to learn PAMI-UK.

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### 6.3.4.7.1 Staff's Views on the Manual

Most staff found the manual informative; however, on its own it was insufficient; the reflective sessions and training were required to supplement the manual.

"It was informative, but it needed explanation... To what the different things were... like you know where there were like different sections to it and what they actually meant" CH03 CK Interview

" It was something that was very new and different phrases that we used different. That's where we lost the categories... it was umm, words and phrases that we weren't familiar with" CH03 CI Interview

The unfamiliar terminology, including Framing and Balancing, made initial comprehension challenging for some. However, with additional clarification and time to process information and become familiar with the terminology, comprehension and confidence improved. More information in the manual defining each section was suggested to improve comprehension further as it would allow staff to consult the manual after the training

While some staff members reported the manual length and layout as sufficient, others felt it needed to be more user-friendly for the intended audience and setting.

"I don't think considering the amount of information that you need I don't think it could have really been done any better... because you do need a lot of information" CH03 CK Interview

"It was quite big, long, we're not used to having a lot of paper to do something... because a lot of stuff is electronic now, it tends to be smaller... it tends to be more concise" CH03 CI Interview

PAMI-UK was considered too long and wordy compared to electronic staff training. CI suggested an electronic manual that was more concise, providing only the essential information would be more suited to the carer's role. CA had opposite views, she believed that the manual was user-friendly if the staff members were motivated to learn.

# "It's user-friendly if they're motivated enough to want to learn and to do it" CH01 CA Interview

CI wanted a portable manual to refer to during shifts, whereas CA only used it to learn the skills initially; the difference in learning methods could have impacted their views of manual suitability. Separating the reflective activities from the theory was suggested to reduce the lengthiness, with the format making it easier to locate practical information while on shift. Additionally, a key point reference document in a small book was suggested as a potential improvement.

"Like (shows a notebook) I don't mean as small as this but a pocket... a little reference thing with key points in it" CH03 CI Interview

Staff did receive a recap sheet before the first reflective session. However, this was a double-sided A4 paper which prevented staff from carrying the information with them during shifts.

### 6.3.4.7.2 Staff's Views on the Interactive Webinar

Overall, staff found the training provided a good foundation for implementing PAMI-UK.

"We thought we were on... a good foot forward on that one. We sort of knew where we were at with that" CH03 CH Interview

However, the flexible intervention structure, including the lack of direct instructions on implementing PAMI-UK, resulted in staff struggling to interpret the researchers' expectations.

"The only thing I found hard at first was knowing... what was expected of of me" CH01 CD Interview

"At first, I think we felt a little lost as we weren't quite sure because we wasn't given set instructions on what to try with residents" CH01 CA Reflective session 1

Staff felt they were not provided with direct instructions on what skills to use, leaving staff feeling lost and unsure on expectations. Although staff initially struggled, they demonstrated implementing skills tailored to their resident's needs.

Three of the four care homes completed the webinar in one session. Staff felt that there was too much information to process in one session. CA felt three hours, whether in one session or two, was too long and could be shortened.

"It was a bit long-winded, I did think sort of towards the end, I think you lost the will, and I think we got a bit sort of side-tracked, and you know three hours was a long time, and it could be shortened a bit... I just think it sort of took a long time to get the point across of what we were expected to do. And then I think people lost the will to live... I think it sort of put people off a bit" CH01 CA Interview

Although she found the training long-winded, it was suggested that splitting the training would allow staff to slowly implement skills, gaining a complete understanding of a smaller set of skills before learning the next set.

Group sessions encouraged group discussion; however, in one care home,

discussions were dominated by one participant.

"The other person that I did training with, I feel like she took control over it a little bit because it was always 'well RA this RA that...' and like I found it difficult to actually put my input into it." CH01 CC Interview

The PAMI-UK facilitators aiming questions at specific participants rather than more general group discussion was suggested to ensure everyone has equal opportunities to discuss their resident.

Staff felt the PAMI-UK training would only be successful if the staff members were willing to learn.

"I think if you've got staff that are willing to learn and wanting to know everything and support dementia residents and improve their quality of life, I think yes, it's a good thing, but I think it is the person you directed to and involved with. They've got to be wanting to improve" CH01 SJ Interview

Staff suggested that if PAMI-UK was a care-home-wide training, different results might be observed when including staff who lack the motivation to learn.

CI suggested that running online webinars with staff from different care homes could aid staff in learning from other care home practices, as she had in other training courses that used this method.

## 6.3.4.7.3 Staff's Views on the Reflective Sessions

The staff found the reflective session helpful in considering ideas with PAMI-UK facilitators and their colleagues.

"The biggest kick I got out of it was the results again, bouncing around ideas, and there were going back to the manual and the things that you and BS sort of throw at us." CH01 CD Interview

The sessions were personalised to the staff and residents, ensuring staff received guidance on implementing PAMI-UK with their specific resident. The personalised element encouraged and reassured them they were correctly implementing the skills.

"I think it's nice to be able to speak about your experience using it, umm, and just getting that bit of encouragement to continue with it. If you're struggling with something or you know, like if you had a win just to be able to celebrate it a little bit" CH03 CK Interview

"I think just to know that you're going on the right track and what you're doing is right, actually just try this or have you tried this or what about this... because I think once you've found a way that works, you think you're a bit low to try anything else because you think, oh I know this works we'll just keep doing that" CH01 CA Interview

CK enjoyed sharing with the researchers when she had experienced a successful interaction. The sessions were an opportunity to celebrate successes while guiding on interactions that resulted in unexpected outcomes. Staff found that the session encouraged them to experiment rather than sticking with successful skills.

The sessions provided time for staff to reflect; on many occasions, staff reported not using PAMI-UK. However, once prompted by the facilitators, they demonstrated multiple PAMI-UK interactions.

"They are useful because it did make me think about what I've actually done differently" CH01 CC Interview

Finding a convenient time for all staff to attend sessions together was challenging and many were reluctant to attend separate sessions.

" I am a bank carer... I do- do two or three shifts a week, but I'm not in more... so I've been able to- been able to attend it while I was here was easy enough... but yeah, because I do something else when I am not here it was a bit difficult for me to actually say well I can come in on my day off" CH03 CK interview Some staff attended during their days off; however, this was unsuitable for staff with other responsibilities.

Despite finding the reflective sessions beneficial, attendance rates were low. CH01 attended half of the reflective sessions, which two participants felt was sufficient.

"I think five enough 'cause I've been able to like reflect on all the different things that helped RC and doesn't help" CH01 CC Interview

The other CH01 participant disagreed and would have preferred to attend all eight sessions.

"I think we should have attended more because I think towards the end I think we sort of lost our way a bit... I seem to lose hope a bit sort of thinking that I'm doing this right and why am I doing this and is it benefiting them" CH01 CA Interview

CA reported that the sessions motivated staff to maintain using the PAMI-UK skills. When her care home missed multiple consecutive sessions, she began feeling lost and doubting the benefits of PAMI-UK.

CH03 had the lowest attendance, with most staff only attending one session. However, staff reported that the lack of reflective sessions was not detrimental to their experience due to meeting as a care home, for individuals to relay reflective session content.

"We did talk about like what was spoken about during the ones that were missed. So, it wasn't like you felt like out of the loop or anything. " CH03 CK Interview

CH03's staff would have preferred to attend more sessions but felt meeting separate from the PAMI-UK facilitators was a sufficient alternative. However, CK attended all three reflective sessions, giving her more opportunities to discuss specific scenarios with the facilitators.

## 6.3.4.7.4 Learning Abilities

Individuals' learning abilities impacted their comprehension; in particular, CC struggled to process the training.

"It gave me the knowledge. It's just like how I am. I just can't process, I have to read them or be told them like several times to actually take it in probably." CH01 CC Interview

When asked, CC was unsure how the intervention could be changed to improve information processing. Some felt comprehension was not achieved until they had an opportunity to implement the skills.

"I'm sort of more a doing it... kind of person rather than read. So, I'm having to put the two together, sort of the written and the the practicality of it." CH01 CD Interview

Having the different types of learning styles helped individuals to understand both the theory and practical elements.

Staff struggled with the quantity of paperwork required for the study. "The filling out the paperwork, I got really confused with that... I am behind on it just because I got confused with it" CH01 CC Interview

"I'm a bit of a stickler for paperwork I've got to sort of sit down this weekend and make sure I've got it all- all sort of sorted out and right for you." CH01 CA interview

CA suggested that researchers observing staff interactions in person could reduce the quantity of paperwork, which could improve staff ability to complete the study.

# 6.3.4.7.5 The Online Format

The training delivery divided participants, with some staff preferring online training due to its convenience and ease of access.

"I don't mind online training because I think it's easier to access sometimes... it's still face-to-face... just through a computer. You're not losing that. What you're telling me now would be no different if you were sat in a room" CH03 CH Interview

CH reported no differences between in-person and online training for her, as the same information is delivered. Others disagreed and preferred face-to-face training as the interpersonal connection was lost in online training.

"Probably face-to-face... because it's you lose the interpersonal thing when it's just a face on the screen." CH01 CD Interview

An in-person element where the facilitators demonstrated and observed the skill in practice was suggested by staff to increase confidence.

"I think you could come in and you could see what we were doing, and then you could give us pointers and show us because obviously the person who invented it and designed it and created it has great expectations, expectations of how it meant to be and what we're meant to achieve" CH01 CA Interview

Additionally, CA believed in-person training would increase attendance rates as it would be harder for staff to ignore the facilitator. Staff felt it was easier to be called away from an online training course compared to an in person one.

There were no practical issues with attending the training; staff could access the Microsoft Teams meeting, and both cameras and microphones worked. The staff in the study were comfortable navigating the software. However, staff suggested that individuals uncomfortable with technology might be less willing or unable to complete the training.

## 6.3.4.8 Theme 8 Implementation of PAMI-UK Within a Care Home Setting

## 6.3.4.8.1 Facilitators to Implementation

Completing PAMI-UK with colleagues was highlighted as a facilitator to implementation, as it allowed them to support each other.

"It was just like we were always there because I I'm my shift are always with CD, CC more or less on the same shift that I'm on... if there was anything that we weren't sure about or you know anything we needed to ask we were just there for each other" CH01 CA Interview

Completing the training together created a sense of togetherness with their colleagues, with many working together in particularly challenging situations. Staff worked together to determine the most appropriate skills for each participating resident, with all the participating staff then incorporating them to increase the resident's PAMI-UK contact. Management support positively influenced implementation.

"Our manager was- was really sort of up for us doing this, gave us the time to think about it more and to maybe do a bit more planning than umm, maybe would have been able to if we didn't have such a supportive management team." CH03 CK Interview The management was accommodating, providing staff with extra time to attend sessions and plan implementation, making using PAMI-UK easier.

CD believed the PAMI-UK study provided them the time and platform to implement psychosocial interventions, which they may have been less willing to attempt if it was not a formal study.

"It gave us the sort of an official platform if you will to sort of to actually do something rather than it being a suggestion that gets, you know, sort of pooh pooh or we haven't got the time to do it." CH01 CD Interview

CD suggested that previously interventions had been suggested but not implemented but having PAMI-UK provided by an outside organisation that monitored progress made staff more likely to implement the intervention.

Although COVID-19 made participating in the study challenging, staff felt that the PAMI-UK skills supported residents during the lockdowns.

"Probably the connecting and balancing more trying to sort of just connect to them and keep them calm because I think we're asking them to stay in their rooms a bit more, and you know, or if they're coming out, people are being sick in front of them, and then that's sort of stressing them out" CH01 CA Reflective session 8

When residents were isolating, CA increased the PAMI-UK skills Connecting and Balancing to attempt to regulate their arousal, reduce stressful situations and connect with them.

## 6.3.4.8.2 Barriers to Implementation

Although CC was participating with two other staff, she worked on a separate floor. She found that the lack of support from other staff on her floor made implementation harder.

"Well, it's a lot harder on my floor to have the change because it's literally just me by myself that doing the PAMI... Where it is a little bit easier for CD and CA because they are on every shift with each other." CH01 CC Interview In CH01 there was little opportunity to work with staff and residents on different floors. Therefore, although CC received support from her colleague in the training, day-to-day, she was implementing PAMI-UK solo. Similarly, CH04's staff member completed the study solo, which she felt impacted her experience and ability to implement PAMI-UK.

Management could be a facilitator but also a barrier when they placed additional responsibilities on the staff due to their success with meaningful interactions and activities.

"she's observing everybody in the home, and she saw that I and CG... we are the best for activities for now before they could get... activities lady to employ, so it's been very hectic and busy." CH02 CE reflective session 6

CE and CG were appointed as temporary activity coordinators owing to their PAMI-UK work when the activity coordinator resigned. Although able to continue using PAMI-UK, the additional responsibilities increased workload and pressures.

Time was highlighted as a primary barrier to implementation; staff schedules were generally full, with little time for meaningful activities or interactions.

"I think the only trouble we would have is having the time sometimes to actually sit and do the engaging, and we have busier times" CH03 CH interview

Although time was highlighted as a barrier, post-training staff were more conscious about finding time to interact meaningfully with residents. Time restraints were not isolated to one care home.

"It's the care industry... we're always busy... that's the frustrating bit sometimes it's finding the time to do it" CH01 CD Interview

Busy schedules with limited available time resulted in high staff stress levels leading to them being less motivated to implement extra activities and interactions.

COVID-19 was a significant barrier, with many care homes experiencing multiple lockdowns. Staff shortage due to sickness led to increased staff workload and

reduced available time, as the remaining staff attempted to compensate for those missing.

"We don't always have the staff that we should have .... On my floor, I meant to have 4 carers and a senior, but like I say, we're not having that, so then you haven't got the time" CH01 CA Interview

Two CH01 staff caught COVID-19 and norovirus, leading to long periods where their residents did not receive PAMI-UK interactions. The extent of sickness in CH01 made the practicality of implementing PAMI-UK challenging.

"That's the only thing that's sort of went against me that at one point then having covid twice and norovirus twice and then with RD being covid and ill as well, everything was sort of at one point it was stacking up against me" CH01 CD Interview

Residents struggled to understand why they were confined to their rooms during COVID-19 outbreaks resulting in staff spending considerable time returning them to their rooms.

"No sooner you get them settled in their rooms then something happens, and they come out, and you sort of so we've not had in the last 2-3 weeks we not had probably the time probably the motivation to get involved as much as we'd like to and what we need to but like I said It was just trying to keep the covid levels down" CH01 CA Reflective session 4

Care home lockdowns were stressful for staff, with their primary concern being to reduce the spread of COVID-19, resulting in non-essential activities being put on hold. Additionally, during COVD-19 lockdowns staff lacked the motivation to engage in the intervention.

Staff felt consistency across shifts was essential to PAMI-UK's success; residents needed to receive the same standard of interactions across staff members. Without consistency, progress made by one staff member was seen as futile, with staff having to reintroduce skills continuously.

"There's no point it just happening on your days it has to happen every day because it's just going backwards, and then you have to get back to square one again" CH01 CA Reflective session. The staff had attempted to incorporate strategies to enable non-trained staff to incorporate the skills into routines; however, there had been resistance.

No personal phone policies made implementing PAMI-UK challenging and stressful for staff as they found phones the most convenient way to provide music.

"We have to get permission to have our phones, for example and we've got 43 residents, so we're not all going to have like the the mechanics to have music in their room... once the stress of having to ask can I take my phone in because I'm doing PAMI today... you think are they gonna let me do it" CH03 CK Interview

The managers allowed staff to use their phones for PAMI-UK; however, the initial asking for permission created additional stress for staff.

Although phones were the most portable and convenient method to deliver music, this made it challenging for other staff to offer the same playlist.

"I don't always get the chance to do the personal thing in the morning, so I had to sort of get your phone organised to give it to somebody else to sort of put it on" CH01 CA Reflective session 2

CA lent her phone to other staff to ensure that RA's morning cueing continued even when not working with her; however, this required planning and was still limited to CA's shifts. During the study, CH04's internet broke, impacting CN's ability to attend reflective sessions. Additionally, her primary music source required internet reducing her ability to implement PAMI-UK.

Care homes being split across floors were common, with staff rotating between the floors, leading to periods when dyads were split.

"We don't always work in the same section of the building. So that could be a barrier. And then I had to find the time to go and see my resident rather than being on shift in her area" CH03 CK Interview

Working on different units led to residents having days with few PAMI-UK interactions. CK did attempt to schedule time to visit her resident, but this was challenging due to her busy schedule. PAMI-UK became an additional task when

working on separate units compared to working on the same floor, where PAMI-UK could be incorporated into daily routines.

Although staff found implementing PAMI-UK with one resident manageable, there were concerns about the ability to scale the intervention in size to include all residents.

"It's really nice. It's a shame I haven't got time to do it with all 43 of them" CH04 CN Reflective session 5

CN had found time in her schedule to offer in-depth, meaningful interactions with one resident; however, she was concerned they would be unable to offer equal time to all residents.

## 6.3.4.8.3 Implementation of PAMI-UK in Care Homes

Initially, staff were sceptical about the intervention being beneficial without adding additional burden.

"To start with it, it seems like just an extra thing to do, and you're like 'oh yeah, I've got time to fit this in somewhere' but I think as it became a little bit more natural... it just became part of what you did in the morning." CH03 CK Interview

As the study progressed; the skills naturally fitted into staff's routines with little alterations to current practices. The two activity coordinators found it more challenging to implement PAMI-UK compared to carers due to their lack of involvement in care tasks.

"I struggle to know when to like implement it... because I do activities, I don't really do like the care I'm not normally there first thing in the morning and stuff." CH02 CP Reflective session 1

Staff could envision PAMI-UK being implemented care home-wide with the potential for long-term implementation. All participants reported planning to continue using the skills post-study.

#### 6.3.4.8.4 Practical Considerations for Implementing PAMI-UK

Knowing the resident before using the intervention was necessary so that staff could assess when residents behaved differently than usual. Being able to recognise cues and behaviours was especially important for non-verbal residents.

"They're not very vocal in communication, but you can you- it's because we see them day in, day out we know that they're normal is" CH01 CD Interview

Having a basic knowledge of the residents assisted staff in developing an initial tailored music plan reducing the risk of unnecessary distress.

For some residents, their medication potentially influenced their engagement with PAMI-UK. CA noted RA's medication influenced her reactiveness to interactions.

"They put her on trazodone because, umm she was- she was struggling now they've taken her off... since she been off of trazodone, she has been a lot more receptive to anything, and she is a totally different person, very much like the person she was when she first came to the home" CH01 CA Reflective session 4

Medication altered the resident's response and, once stopping the medication, she engaged more with music. Similarly, CG felt the side effects of the medication were causing high levels of agitation in RG, leading to futile outcomes when using PAMI-UK. Administration of some medications are unavoidable; however, CA suggested that staff provide medication as a quick solution to manage challenging behaviour instead of using PAMI-UK.

"The night staff are just quite happy to give her lorazepam, and I said... just put her in the bedroom just put a music station on the telly she will sit for hours if she's got music on" CH01 CA Interview

The night staff typically opted for medication to manage RA's high anxiety and restlessness rather than using music.

Providing music devices in bedrooms relied heavily on the involvement of families.

" If we can get the family to buy an Alexa or you know cause Alexa aren't that expensive now" CH01 CA Interview

The involvement of residents' families extended the opportunities of implementing PAMI-UK. Personalised plan and supporting staff in PAMI -UK interactions, providing staff with more opportunities to implement PAMI-UK.

"I've got listed RA's favourite songs... it's all the music that they played with her when they take her out" CH01 CA Reflective session 1

RA's family were equally engaged in the music intervention as staff, with them buying her headphones and music devices to support RA's music care and using the same playlist to regulate arousal to maintain consistency. Similarly, in CH02, involvement of a resident's wife positively influenced the implementation by providing his preferred music. Families who visited regularly were easier to engage in the intervention; however, when families were harder to contact, initial implementation was more complicated due to staff having to discover the resident's preferred music before being able to implement the skills.

"It's trying to get catch them... we phone them, and we ask them can you write a list of their favourite music is that's as far as you're aware, and then they have to go back and think about it. And it's like CD's it's two of her sons that haven't seen her for quite a while due to covid, so it's having them recap what she used to listen to quite a long time ago that was very difficult where CC you've seen RC's husband and his writing a list" CH01 CA Reflective session 1

CD struggled to obtain the required music information from RD's sons, making it harder to implement PAMI-UK initially. In contrast, CC interacted with RC's husband daily, enabling her to receive his constant input throughout the study.

Most families' involvement was beneficial; however, for one resident, their involvement led to negative outcomes.

" I think the husband is- is wearing a hearing aid, so I think he's- he's not hearing properly, so he likes everything to be loud... I noticed anytime the husband is around, and he has music in the room, the wife is always agitated" CH02 CE reflective session 4

CE observed that the resident became agitated when her husband visited because he increased the radio's volume. The staff attempted to make changes to improve the resident's agitation, but the husband argued and disagreed with the staff's observations.

Although dementia severity could influence using PAMI-UK, staff agreed that music remained accessible to all residents if the intervention was adapted to their needs and impairments.

"I've used it with all the residents I interact with. If the opportunity is there, I use it because that's one thing that all the residents, whatever their level of dementia is they will interact to music every single one of them." CH03 CH Interview

Residents could engage in some form of music regardless of dementia severity, as demonstrated by RH, who was in the advanced stages of dementia but interacted and engaged in PAMI-UK interactions on several occasions.

Music preference was highlighted as an essential element of implementing PAMI-UK. Unfamiliar or disliked music could lead to disinterest and disengagement from residents.

"She was shouting out and saying she wanted to die.... I was playing some hymns... it's just one I remembered from when I was at school... so I put the tablet nearer her, and she wasn't a bit interested. But then, (admin)... she goes to the same church... she told me something else to put on, another hymn to put on, and she responded to that... So, me just presuming that any old hymn that's in my repertoire would be okay wasn't. I needed to get the right one." CH03 CJ Reflective session 3

CJ initial attempts to regulate arousal was unsuccessful due to the selected music. The CH03 staff were very knowledgeable of their residents' history Pre-PAMI-UK. However, this interaction taught CJ more about the importance of meaningful music. CJ believed any religious music was appropriate as the resident was religious. In contrast, staff reported meaningful music evoking emotions and reminiscence for some residents.

"There be certain songs come on and it you can-you can see. this just havinghaving music on certain songs evoking reactions from residents that you really want normally get a reaction out of." CH01 CD interview

During the training, staff began selecting music more consciously. Selecting appropriate music, particularly the right music at the right time, was challenging for staff; however, when music evoked a positive resident reaction, staff felt rewarded for their efforts. "Finding that specific genre of music that they like, and going with it is- it is really sort of been quite, It's been quite challenging, but it's been really rewarding as well. "CH03 CK Reflective session 5

External factors, both controllable and uncontrollable, influenced Implementation. During the study, two national events occurred, the Queen's Jubilee and her death; during these periods, staff found implementation outside of personal care challenging due to other activities occurring.

"It's been kind of crazy the past few weeks because that we've been doing the Jubilee and staff, and it's such a big home that like it's quite busy. So, I've struggling to have the one-to-one time with the resident" CHO2 CP Reflective session 1

The activity coordinators were encouraged to offer activities relating to the Jubilee, which they felt left little time to incorporate 1-to-1 musical interactions into their schedules. Similarly, when the Queen died residents were more engaged in watching the news rather than engaging with music.

One care home had a high staff turnover during the study, including the care home manager. Staff were assigned additional responsibilities to composite for staff shortage, impacting PAMI-UK implementation.

"We have a new manager now, so everything is changing everybody is leaving we are having a new everything." CH02 CE Reflective session 6

The multiple changes increased staff stress and reduced available time to implement PAMI-UK. Despite the limited time, the staff fully engaged in the training and intervention.

## 6.4 Discussion

#### 6.4.1 Key Findings

All participating staff members demonstrated an in-depth understanding of PAMI-UK, with them tailoring the intervention to their residents' needs, preferences, and abilities. Staff had begun incorporating skills with both participating and nonparticipating residents. Some of the outcomes from this study were similar to those presented in the manual field-testing study (Chapter 5), while also presenting new findings.

From the quantitative outcome measures only the SCIDS total score and the subscale residents' tense restless behaviour on the QUALIDEM reported a significant difference. The increase between the pre and post SCIDS score suggests that PAMI-UK training made staff feel more able to care for their residents with dementia. The difference between the pre and post tense restless behaviour subscale suggests that staff perceived residents as having less restless tense behaviour post-PAMI-UK implying a higher quality of life in this domain. As the study had a small sample size of six dyads the quantitative analysis must be considered with caution, and conclusions cannot be drawn from the data. However, the quantitative data follows similar trends to those presented in the qualitative data.

# 6.4.1.1 Staff Awareness

Staff developed a greater awareness of themselves, their residents, and the care home environment. Staff recognised the impact of their voice and low-fidelity noise environments on their interactions with residents and, where possible, were able to modulate them successfully. Staff also became more conscious of when and where interactions would take place and took more time beforehand to minimise the impact of themselves and the environment on these interactions. Pre-PAMI-UK staff interactions consisted mainly of task-orientated elements, compared to post-PAMI-UK, where staff actively sought opportunities to interact with residents meaningfully.

#### 6.4.1.2 Resident and Staff Outcomes

Music was used during tasks to regulate, cue and frame, improving residents' moods, reducing agitation, and increasing resident cooperation. Music during mealtimes increased residents' focus resulting in increased food consumption and independent eating. Previous research investigating music at mealtimes also reported an increase in food consumption in addition to improvements in physical aggression, verbal agitated behaviours, irritability, fear-panic, and depression (Ragneskog et al., 1996; Whear et al, 2014). In Ragneskog et al (1996) residents may have had increased food consumption resulting from staff serving larger portions during the music condition. Staff's behaviours during music at mealtimes was not reported in the PAMI-UK study.

The grounding skills for regulating staff's arousal reduced stress enabling them to offer more energy in their PAMI-UK interactions. Overall, staff experienced reduced stress and increased happiness, potentially due to residents' being more relaxed, aware, happier, and more cooperative in tasks. Lee et al. (2022) similarly reported that staff's mood and experience was impacted positively by the resident behaviour change.

## 6.4.1.3 Staff-Resident Interactions

Although many residents had limited verbal communication, they could continue interacting through other, more accessible communication forms such as singing, humming, dancing, smiling, and physical touch. PAMI-UK participants reported similar experiences to staff in the 'creative conversation' study, both seeing changes in residents' eyes during interactions and knowing the resident was present in the moment (Windle et al., 2020). As non-verbal communication is more subtle than verbal, residents' attempts to initiate interactions are often missed (Ward, 2008). PAMI-UK facilitated the staff's ability to perceive and comprehend residents' nonverbal communication, enabling them to interact effectively with residents and sustain meaningful interactions. The staff were attuned to residents' emotional needs, enabling the deployment of appropriate personalised care and support. Similar to Söderland et al. (2011), who explored validation methods in

communication, this study found that attuning to the resident made managing challenging situations easier and softened the relationship between staff and residents.

Initially, some staff reported being unable to complete one-to-one interactions. However, as the study progressed, PAMI-UK became more natural, with activities and interactions spontaneously incorporated when opportunities arose. Sometimes, staff reported interactions as unremarkable, due to minor resident responses. Although minor reactions these interactions were still significant to a usually isolated individual. Residents in the later stages of dementia can display limited reactions and high apathy (Humphrey et al. 2019). However, PAMI-UK remains accessible compared to other interventions, with the skills evoking some reactions in late-stage residents, which pleasantly surprised staff.

Windle et al.'s findings (2020) suggested that interactions outside planned activities may be the most authentic staff-resident interactions. Similar to PAMI-UK previous research has highlighted that meaningful interactions do not need to consist in lengthy pre-planned activities instead they can be weaved throughout the day spontaneously at times most appropriate for both the staff and resident. Additionally, due to these interactions generally being shorter and because of PAMI-UK's flexibility, these types of interactions do not add additional time or burden to the staff routines.

Pre-PAMI-UK, residents in this study who required additional support to engage in activities and interactions were overlooked, leading to isolation. Whilst dementia symptoms can result in staff needing to initiate and maintain interactions, residents' inactivity can deter staff and exacerbate this disconnection. The extra support post-PAMI-UK enabled residents to engage in music activities and interactions which were otherwise absent, changing the staff's perception of them and creating a more positive, two-way interaction. The change in interactions could strengthen residents' personhood, with staff providing residents with recognition, respect, and trust

(Brooker, 2004; Kitwood, 1997). The VIPS framework (Brooker, 2004) details four principles of person-centred care, which PAMI-UK aims to situate interactions within, therefore, aiding residents' sense of personhood and overall well-being.

#### 6.4.1.4 Person-Centred Care and Personhood

Residents can experience a loss of identity when entering long-term care (Thein et al., 2011), being perceived as a patient who are reduced to their symptoms, especially when they are inactive or unemotive resulting in further isolation (Heggestad et al., 2015). The dehumanisation can lead to a loss of personhood. PAMI-UK aided staff in acknowledging the individual behind the diagnosis who continues to have the needs, likes, and wishes of a 'healthy individual'. Acknowledging comparisons between themselves and residents resulted in staff acknowledging the individual as a person, leading to them providing for the needs of the person, not the condition. Furthermore, when staff imagined a family member in the resident's position, the residents were humanised, with the care of residents becoming an emotional response compared to a practical one. Staff in other study have reported that 'putting themselves in the resident's shoes' resulted in them experiencing increased empathy (Rapaport et al., 2017).

The relational dynamic between care staff and residents consists of a power imbalance. Care staff can view residents as passive objects solely dependent on them, developing a 'doing for' relationship (Novy et al., 2022). 'Doing for' relationships are not built on trust, respect, and reciprocity, potentially leading to staff feeling a sense of powerlessness and loneliness in interactions (Hammar et al., 2010) and the resident's personhood being negatively impacted. Opposingly, 'Doing with' relationships involve staff and residents working together (Novy et al., 2022) which were demonstrated by staff focusing on residents' abilities rather than impairments. PAMI-UK increased resident awareness and reduced agitation enabling residents to be more independent in tasks, with staff providing support rather than dependency. In doing this, PAMI-UK facilitated the (at least partial) transition of staffresident relationships from 'Doing for' to 'Doing with' dynamics.

The power imbalance altered on occasions when the residents taught staff new skills. Allowing residents to teach others gave the resident worth and purpose during the interaction, demonstrating the occupational petal of Kitwood's (1997) emotional needs flower. The other emotional needs in Kitwood's flower were also demonstrated during the study. Staff sharing their personal life history could also help develop relationships and help reduce the power imbalance, with the interactions being between individuals rather than 'carer and patient'.

#### 6.4.1.5 Staff Perception of Problematic Behaviour

Residents' behaviours can be considered problematic and solely misconstrued as a dementia symptom, or staff may even consider the behaviour deliberate to gain attention (Cohen-Mansfield, 2000). Staff's perception of problematic behaviour influences their treatment decisions. Considering residents' behaviours in terms of the medical model can result in increased medication use (Innes & Manthorpe, 2012). Non-participating staff preferred providing medication to reduce restlessness compared to the resident's personal playlist. The preference for medication over music may be due to it being perceived as being easier and quicker to administer (Kolanowski et al., 2010; Strøm & Engedal, 2021). Alternatively, some staff are sceptical of music as an effective treatment. Additionally, non-participants lacked the knowledge of using music to regulate arousal due to not completing the training (Strøm & Engedal, 2021), which could influence their decisions.

Participating staff acknowledging 'problematic behaviour' as a form of communication when alternative communications was unavailable, is supported by Kitwood's person-centred theory (1997), who suggested problematic behaviours is a way for individual to express their unmet needs. Staff, facilitated by PAMI-UK training, demonstrated using Validation Theory (Feil, 1992, 1993) to aid residents in working through anxiety, repressed memories, and emotions by providing them time and an opportunity to interact. Changing the perception of 'problematic behaviours' resulted in increased staff empathy and interactions providing comfort and understanding.

PAMI-UK reflects similar elements and principles to intensive interactions (Heap & Wolverson, 2020). Both aim to highlight two-way interactions between individuals with and without dementia using communication skills that match the individuals with dementia's abilities and needs. PAMI-UK and Heap & Wolverson's (2020) study displayed similar results, with staff altering their perception of residents with dementia post-training. Behaviours such as tapping were considered forms of communication which staff could mirror rather than aimless tapping or problematic behaviour.

#### 6.4.1.6 Implementing PAMI-UK

Staff participants were enthusiastic about PAMI-UK and highlighted the benefits. However, there were concerns from participants that not all staff would display the same enthusiasm. Staff implied the training may not be suitable for all staff and that they may need to possess sufficient personal qualifications. A similar consideration was raised in Söderlund et al (2012), who suggested that attributes such as attentive listener, maturity, and patience could influence staff ability to use the interventions. Both PAMI-UK and the Validation method (Söderlund et al, 2012) were seen as emotionally demanding and involved, which could require staff to be motivated to learn and change their current practices. When some participating staff encouraged non-participating colleagues to use PAMI-UK skills to maintain consistency, they were met with resistance, with some suggesting that music is ineffective. Other research has documented resistance from other care staff as a barrier to implementation (Groot Kormelinck et al., 2020; Rapaport et al., 2017).

Additionally, some barriers could have been preventing non-trained staff from implementing skills. Current care home practices, policies, and available resources could result in staff needing to provide additional time, effort, and motivation decreasing the likelihood of some staff implementing PAMI-UK (Kaasalainen et al. 2010). Ensuring devices and music are easily accessible to all staff could increase the chance of other staff incorporating the skills despite not receiving training.

Many staff possess the characteristics and skills to provide meaningful interactions pre-PAMI-UK but lacked the confidence, terminology, or opportunity to explore and implement them as highlighted by staff in both this study and the manual fieldtesting study. Previous research has highlighted that communication training can provide staff with the language to describe their experience in greater detail (Söderlund et al, 2012). Staff were enthusiastic about implementing music, but psychosocial interventions can easily become a low priority due to limited time and workload. PAMI-UK provided staff with a platform to reassess their current practices and explore new skills while having the comfort of gaining guidance and support.

#### 6.4.2 Recommendations for Changes to the Intervention

Feedback on the cultural appropriateness of the intervention was collected to aid the revisions. Overall, staff reported the intervention as useful and informative and could be easily implemented in care homes. The intervention was generally considered suitable for its intended audience and setting; however, some suggested changes could improve suitability further. Compared to other staff training, PAMI-UK was considered too long. A shorter online manual could make the intervention more suited for a carer's role. Additionally, with an online manual, a function allowing staff to navigate from the content page could improve the effectiveness of locating specific information. Some staff suggested a reference sheet that define categories clearly. A recap sheet was provided before the first reflective session; however, it may be more suitable to provide it with the manual. Additionally, one staff member suggested providing the information in a small booklet that could be carried on shift.

Staff who felt the webinar was too long suggested splitting the session into two. All care homes were offered the two-session option; however, only one chose this option. As staff commented on the training length, only offering the training as two sessions may be more suitable. In some sessions, specific individuals dominated discussions leaving little time for others to speak. In future sessions, training facilitators should be more observant and direct discussions to ensure all participants

contribute. The reflective sessions' lengths were too short for larger group sizes; offering additional individualised sessions could ensure that all staff members receive tailored supervision.

Staff were divided on their preferences for the training format. Some preferred online training due to its ease of attendance, while others missed the personal aspect of in-person training. An in-person observation session where the facilitators monitor staff using the skills could make staff more confident in their implementation.

#### 6.4.3 Methodological Difficulties and Limitation

#### 6.4.3.1 Dropout Rates and Data Bias

A high staff dropout rate due to high staff turnover and workload pressures resulted in a small sample size. Of the personal parameters measured, there was no significant difference between staff who completed all study elements and those who dropped out before completion, with exception for years in dementia care. Although the other personal parameters measure reported a non-significant difference in the two groups there is a potential of a type two error due to the small sample size. Additionally, not all dropouts returned completed documents up to the point of withdrawing; therefore, it is difficult to determine if there was a difference between these individuals that could somewhat predict dropout rates. The staff suggested their workload or stress was not increased from participating. However, some participants dropped out due to workload pressures; therefore, available results from this study could be biased toward those able to facilitate a high workload, potentially biasing towards more prolific carers.

Additionally, there were high levels of missing data and a low questionnaire return rate, despite the research team continuously attempting to obtain the questionnaires for several months post-intervention. The high levels of missing data and low return rates resulted in a small sample size. The small sample size means that no conclusion can be made from the statistical analysis of quantitative measures

obtained throughout the study. Instead, they were only conducted to provide insight into potential patterns to explore in later studies with a larger sample size.

### 6.4.3.2 Conducting the Study Remotely

One explanation for the missing data and low questionnaire return rate could be due to the study being conducted remotely; a limitation imposed by restrictions in place during the COVID-19 pandemic. It was difficult to contact care homes to organise reflective sessions and the collection of documents, particularly the collection of post-questionnaires. Additionally, due to using online delivery the researchers relied on the staff to report the use of PAMI-UK and interactions they were having. Firstly, remote delivery made it difficult to determine whether staff had implemented the PAMI-UK intervention or music in general. Secondly, when reviewing the transcripts, it became apparent that staff had referred to multiple residents, introducing uncertainty as to whether staff were reflecting on their paired resident or another, non-participant, resident. This may have introduced misinterpretations of some transcript passages.

### 6.4.3.3 Self-Reported Questionnaires

Data was self-reported, increasing the chance of social-desirability bias (Duffy et al, 2009; Gerritsen, 2019). Staff may have been less likely to document when they could not implement PAMI-UK, or behaviours considered negative. Adding in-person observations where the PAMI-UK facilitators observe interactions could reduce the chance of social desirability bias and enable the researchers to determine that all interactions reported are with participating residents. However, staff could see observations as inspections rather than data collection, increasing anxiety and introducing additional behaviour bias.

#### 6.4.4 Clinical Implementation

These results provide further support for the benefits of music in care homes in general, as well as the potential benefits of PAMI-UK. PAMI-UK can potentially impact residents, staff, and the care home environment. However, staff's reports of implementation barriers suggests that PAMI-UK should be implemented as a care-

home-wide intervention with all staff trained to maintain consistency and reduce or eliminate barriers. The intervention can aid care homes in changing staff-resident interactions with staff moving from task-related relationships towards personcentred relationships where residents are treated with respect, trust, and reciprocity, positively impacting their personhood and well-being. The skills are implemented into daily routine with little additional staff burden or work pressures, increasing the likelihood of staff using the intervention. However, staff potentially need to be motivated to change and learn for successful implementation, such as if they feel that they have nothing new to learn from training or consider psychosocial interventions a waste of time (Emilsson, 2006).

## 6.4.5 Future Research

This study was built upon on the foundations of the PAMI-UK manual field-testing study (Chapter 5) and continued to target phase 3 of the cultural adaption frameworks. Additionally, the study began to target phase 4 which aims to review and evaluate the culturally adapted intervention for its impact on the intended audience. Further studies are required to investigate the impact of PAMI-UK on staff and residents, with particular emphasis on the collection of complete quantitative data to assess the manual's effectiveness and efficacy. From this study, recommendations were made to continue to improve the cultural appropriateness of the manual, including reassessing the training length, reviewing the recap sheet, and introducing in-person observation sessions. The recommendations should be tested in future studies to complete phase 5 of the cultural adaptation frameworks: finalising the culturally adapted intervention.

## 6.4.6 Conclusion

Staff were able to tailor the PAMI-UK intervention to their resident's needs, preferences, and abilities, resulting in improved mood, agitation, communication, food consumption, and overall well-being of residents. Additionally, staff observed improvements in their stress levels, dementia awareness, and mood. Staff found the

manual culturally appropriate for UK care homes and suggested changes that could improve suitability further. Due to the small sample size and high degree of missing data, quantitative data could not be meaningfully interpreted. Therefore, further research is needed that continues to explore the impact of PAMI-UK using quantitative outcome measures, with implementation of appropriate measures to increase participant retention and study completion rate.

# 7. Discussion

# 7.1 Introduction

This doctoral study aimed to develop and evaluate a UK version of PAMI, which was culturally appropriate for UK care homes caring for residents with dementia. The intervention was developed using the MRC complex intervention guidelines, particularly stage 1- development and stage 2- assessing feasibility and evaluating methods (Craig et al., 2008). Initially, the project gained expert consultations from care staff and the Danish PAMI team to gain a greater understanding of both the PAMI intervention and UK care homes' needs to ensure that the intervention was appropriate for its intended audience and setting while maintaining PAMI's primary principles, theory, and skills. A systematic review was conducted to explore current music interventions that facilitate social interactions to investigate the mechanisms that may explain the facilitation and to gain insight into the facilitators and barriers to implementation. The systematic review enabled the researcher to consider components of music interventions that facilitate resident-staff interactions, and which may hinder them. Previous research on culturally adapting interventions guided the translation and adaptation stages (Aguirre et al., 2014; Tol et al., 2018; Werheid et al., 2021).

Once the manual was developed, a field-testing study explored the staff's experiences and views on the intervention to review the suitability and cultural appropriateness. The final study continued to explore suitability and cultural appropriateness while also investigating the study design's feasibility and outcomes for future studies' development.

Originally, the project aimed to complete both studies in-person; with the primary researcher conducting all study elements and facilitating the PAMI-UK sessions. The COVID-19 pandemic resulted in the research team redeveloping the study design in alignment with care home restrictions whilst aiming to keep robustness. This chapter considers the project's strengths, limitations, and recommendations for future studies.

# 7.2 The Development of PAMI-UK

### 7.2.1 Cultural Appropriateness

The researchers included staff's ideas and feedback throughout the project to ensure the manual was culturally appropriate. A clear link between the initial expert consultations and the manual elements is apparent, which was then highlighted by participants in the studies. Staff in the studies reported that the PAMI-UK manual was easy to use and well informative.

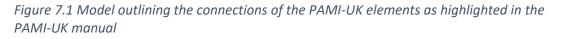
Due to the change in care homes during the COVID-19 pandemic, the main aim changed to not only accommodate the cultural needs of UK care homes but also to accommodate the continuous and uncertain changes in care homes during COVID-19. The staff's insight was invaluable to ensure both needs were accommodated, as there was no previous research into global pandemics and lockdowns to guide the researchers. The staff in the studies did not feel that the required changes to accommodate COVID-19 hinder their experience or their ability to discover PAMI-UK.

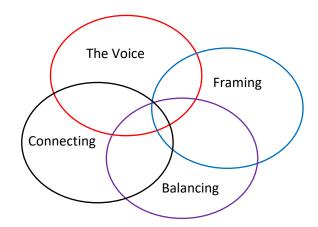
Staff demonstrated using and adapting PAMI-UK skills to align with residents' needs, preferences, and abilities. Staff's feedback and demonstration of using the skills suggests that the UK manual was adapted suitably for UK care homes. Published articles from the original Danish team (Krøier & Ridder, 2022; Ridder et al, 2023) reported similar results for PAMI-DK, suggesting that PAMI-UK maintains the original principles and ideologies while ensuring it is culturally appropriate for the UK. The researchers aimed to make PAMI-UK culturally appropriate by reducing the training length, directly training staff rather than training music therapist to deliver the staff training and alter the PAMI element terminology. Despite a non-music therapist facilitating the training and altering the clinical shadowing to reflective discussion sessions, staff implemented the skills and demonstrated developing trusting and reciprocity relationships through musical interactions similar to the staff in Krøier & Ridder's (2022) study. Both sets of staff used musical interactions with similar intentions, to connect, complete tasks, bring comfort, and reduce anxiety.

## 7.2.2 Intervention Elements

Within the training, PAMI-UK elements are introduced as linking but individual entities (Figure 7.1). From the results, it can be inferred that each interaction can consist of a combination of elements that interconnect, overlap, or become prominent as the interaction occurs. Initially, an individual may use music to regulate a resident's arousal, but as the resident's arousal levels reduce, the interaction can evolve to allow music to be used to connect. Figure 7.2 may present a more accurate representation of how the PAMI-UK elements interact with each other during musical interactions. Future PAMI-UK training would incorporate the adapted model developed during this project.







*Figure 7.2 A model displaying the connections of the PAMI-UK elements based on the results from the study* 

## 7.2.3 PAMI-UK Key Components

Staff demonstrated and discussed the fundamental principles of PAMI-UK as highlighted in the manual. PAMI-UK is adaptable and inclusive, making it accessible to residents regardless of dementia severity. As music processing remains intact through the dementia stages (Garrido et al., 2020), the PAMI-UK skills can enable residents with moderate to severe dementia to continue to connect with others, aiding the maintenance of their identity and personhood (McDermott et al., 2014b; Hsu et al., 2015).

Staff can see music as solely entertainment rather than treatment owing to a lack of training in integrating care home music interventions, resulting in lower-quality music activities implemented (Garrido et al., 2020). Music in care homes generally consists of live or recorded music listening with no active interaction between residents and staff (Garrido et al., 2020, 2019). The PAMI-UK intervention provides staff with training not only in implementing the skills but also raises awareness about the therapeutic benefits of music when used as a treatment. McDermott et al. (2018) highlighted that music training needs to focus equally on how the facilitator (staff in PAMI-UK) delivers the intervention as much as the content. In PAMI-UK, staff discover how to be with the residents, learning skills to increase person attuned musical interaction rather than just how to increase music in care homes.

Care homes, staff, and residents are a heterogeneous group; thus, flexibility was essential to accommodate differences, as suggested in previous research (Lawrence et al, 2012; Smith et al, 2019). PAMI-UK needed to be adaptable both between and within residents to enable the skills to meet each individual's needs, preferences, and ability, as well as be able to be altered as their dementia progresses. The training also required flexibility to allow the material to be altered to align with care homes and individual staff member's personalities, learning styles, experience, and current practices (Groot Kormelinck et al., 2020).

Many staff initially struggled with the lack of direct instructions, as the manual does not provide step-by-step instructions on implementing PAMI-UK. They would have preferred being told what skills to implement and when. However, as the studies progressed, staff demonstrated implementing the skills in relation to their resident, suggesting sufficient comprehension. Frequent adapting and altering of the intervention may not have been viable with a more structured format. Hackett et al. (2021) argue that many music interventions set one goal for all residents without

considering individual needs and impairments, resulting in only residents whose needs aligned with the goal benefiting.

A fixed and structured manual with step-by-step instructions can lead to the setting of singular goals, compared to a flexible manual that enables individualised goals and tailoring to the resident. At the same time, as highlighted by staff, a flexible manual that only provides guidelines can lead to participants feeling lost and unable to link the guidelines to specific practical scenarios (Hannibal et al., 2019). Although PAMI-UK aims to be flexible, the addition of reflective sessions enabled staff to gain insight into the practical implementation. Using staff's experience to guide sessions ensured the intervention remains tailored and person-centred. Adding fortnightly goal setting in the second study provided more focus, enabling staff to link the skills more directly to current challenges, linking back to Hackett et al.'s (2021) recommendations. The framework used for PAMI has been described as a sequential procedural framework (Anderson-ingstrup, 2020). The manual highlights different goals but allows the user to choose between different techniques (Andersoningstrup, 2020). PAMI is based on person-centred philosophy, where staff choose the skills based on their resident's mood, arousal, and needs during the interaction (Kitwood, 1997).

#### 7.2.4 Using PAMI-UK

The results from both the field-testing study and manual evaluation study reported staff using the PAMI-UK skills for similar purposes, with staff reporting similar staff and resident outcomes. Although residents' engagement levels and PAMI-UK's purpose changes depending on dementia severity, meaningful interactions remain vital and accessible to all residents. In study one, it was suggested PAMI-UK during end-of-life care was inappropriate, due to singing and music being disrespectful. However, in study two, PAMI-UK was used to bring comfort to both the resident and staff member during end-of life-care. When residents are on end-of-life care interactions may be limited, however, they can continue to connect with others through music to bring comfort and strengthen relationships through the shared

experience, creating a sense of belonging for the resident (Black & Penrose-Thompson, 2012).

Lawrence et al. (2021) suggested that when short on time, managing problematic behaviours takes precedence over psychosocial interventions, with staff attempting to complete tasks as quickly as possible rather than considering the most appropriate delivery for the resident. However, the studies highlight that staff can incorporate both into care tasks, potentially resulting in better outcomes for staff and residents. By incorporating individualised musical interactions into tasks, staff can ensure that residents' psychosocial needs are met while completing the necessary tasks. The PAMI-UK skills can orientate the resident, reduce agitation, and improve resident cooperation resulting in tasks being completed quicker with less 'problematic' behaviours and a more pleasant experience for both parties. The MTC studies reported similar results when implementing singing into morning care (Hammar 2010, 2011a, 2011b, 2011c; Götell 2009, 2010)

Overall, staff reported positive resident outcomes when implementing PAMI-UK; however, there were some instances where residents displayed unexpected or negative outcomes to musical interactions. The training aimed to guide staff in managing negative outcomes to reduce the chances of residents experiencing adverse effects whilst also recognising that a negative response did not mean that music is ineffective (Garrido, 2020; Krøier et al., 2020); a concept other music interventions lack (Batt-Rawden & Srorlien, 2019).

Sometimes, the negative or unexpected outcome was interaction specific, depending on the resident's current state. Whilst in other cases, all musical interactions resulted in negative outcomes. Music is multi-factored and complex; therefore, the intervention required substantial staff knowledge of the resident for staff to monitor potential harm (Silverman et al., 2020). Staff were aware when an interaction caused harm or distress and needed stopping immediately compared to an interaction that used the wrong skill at that specific time point. All the staff participants were aware

that music is not universally enjoyed, this awareness is not present in all staff implementing music interventions (Garrido et al., 2020), and this mind-set can increase the chance of music-induced harm (Silverman et al., 2020). Music-induced harm describes both physical and psychological harm resulting from music including music-induced hearing loss, identity harm, affective harm, spiritual distress, reduced attention, music-induced trauma, increased agitation and experiencing painful memories. Tailoring the intervention to each individual and aligning music to the resident's current arousal state can reduce the likelihood of residents experiencing adverse effects (Garrido et al., 2019).

# 7.3 PAMI-UK in the Context of Current Research

PAMI-UK aligns with the Integrated Model of Music Care (IMMC) developed by Foster (2021), which encourages music integration into care by training individuals in music techniques regardless of their prior musical knowledge. Similar to Foster's study, training staff in music skills that could be incorporated into current practices increased staff confidence and knowledge, enabling them to develop tailored intervention plans targeting at specific challenges. Encouraging interventions that provide non-musical individuals with music skills traditionally reserved for music therapy increases the accessibility of music interventions, especially in care homes that are unable to employ a music therapist.

Staff perceived PAMI-UK as requiring staff to completely change their mind-set. During the staff consultations, individuals were concerned that staff with a 'get the job done' mind-set would be reluctant to implement PAMI-UK. Wilson and Davis (2009) proposed three staff-resident relationships: task-, resident- and relationshipcentred. Staff who develop task-centred relationships mainly aim to provide highquality physical care, with individualisation developing through caring for the resident rather than getting to know them. They are less motivated to develop personal relationships resulting in residents' physical health and safety being the sole priority (Wilson & Davis, 2009; Garrido et al., 2020). Task-orientated relationships align with the medical model, which can be encouraged by care cultures as it promotes routines rather than social interactions (Lawrence et al., 2016).

PAMI-UK encourages staff to have relationship-centred relationships with staff discovering the resident's individuality through social interactions which allows them to tailor the residents care to their needs and preferences. Relationship-centred relationships differ from resident-centred ones as they consider the individual's needs in the context of other residents and staff's needs (Wilson & Davis, 2009). Through resident and relationship-centred relationships, staff discover the person behind the diagnosis, allowing the implementation of meaningful details into care and enabling residents to maintain their identity. Relationship-centred care creates a sense of community within the care home, with residents and staff recognising their contribution, as seen when residents equally shared personal information leading to them connecting and developing a personal relationship compared to a care one. Developing a personal relationship potentially leads to residents cooperating more with participating staff compared to other staff (Bowers et al., 2001; Wilson & Davis, 2009).

Care homes have evolved significantly since the 19<sup>th</sup> Century when individuals were seen as incurable and unmanageable (Andrews, 2017). Organisations are now promoting person-centred care where individuals are involved in care decisions and recognised as a whole person rather than their condition. However, time pressures, high workloads, and lack of training and resources can result in person-centred care being easily overlooked (Kong et al., 2020). PAMI's central ethos is to promote person-centred care, with physical health and safety prioritised equally as psychological and social needs. Embedding musical interactions into current practices reduces and eliminates previous barriers. The musical interactions make residents equal partners regardless of their language abilities by encouraging staff to recognise subtle communication cues, which they can respond to appropriately (Coates & Fossey, 2019). Residents can become more independent with relationships

built on 'doing with' rather than 'doing for', helping individuals maintain an identity and be considered a person rather than a patient (Novy, 2022). Moving away from the medical model towards a person-centred model has the potential to reduce the use of medication and increase well-being among residents with dementia (Li & Porock, 2014; Batt-Rawden & Stedje, 2020).

### 7.4 Implementation

Psychosocial interventions must be considered in the context of a care home setting, which could influence implementation.

#### 7.4.1 Specialist Equipment Requirements

PAMI-UK does not specify the need for specialist equipment, care staff can use their voice or music devices their care home already own, making the intervention more accessible to a wider care home population, including those with restricted finances. However, previous research has suggested that the music equipment in care homes is inadequate, or not cared for sufficiently limiting the practical implementation of music interventions (Garrido et al., 2020).

In general, staff found their personal phones the most convenient devices as they were portable, easy to use, and music-streaming apps provided an extensive music catalogue. Many residents have restricted access to music devices in their rooms; therefore, phones enabled staff to access music anywhere in the care home. Using personal phones reduced the barrier of care homes having minimal music devices. However, care homes with a no-phone policy could prevent the accessibility of interventions, especially if the care home has limited alternative music devices (Fosters, 2021). Additionally, care homes should not expect staff to use their personal phones for their job. Some care staff may not have a smartphone that is equipped with music-streaming apps or pay for the premium version. Care homes should ensure that staff have access to sufficient music devices to enable them to offer a high-quality version of PAMI-UK that do not rely on staff's personal resources and finances. Although no specialist equipment is required for PAMI-UK, access to music devices, especially in residents' bedrooms, improved PAMI-UK

implementation. Therefore, residents in care homes with limited finances could still be disadvantaged (Lawrence, 2016).

## 7.4.2 Management Support

Management support is vital for successful implementation (Garrido et al., 2020; Lawrence et al., 2012, 2016; Surr, 2019, 2020). When managers see the results for residents, staff, and the care home environment, they can make changes to accommodate the intervention and encourage staff to use it. The managers encouraged staff to engage in the project by providing support, accommodations, and time to attend sessions. Involving management in interventions can lead to care home culture changes within the home (Lawrence, 2012), of which early signs were apparent in this project.

## 7.4.3 Time Restraints

Time restrictions are common barriers highlighted in psychosocial interventions research due to high workloads and staff shortages (Stanyon et al., 2016; Windle et al., 2019; Savundranayagam et al., 2014). Compared to structure time-specific interventions, the PAMI-UK format reduced time pressures with staff implementing musical interactions in short, frequent increments throughout the day while engaging in other tasks (Lawrence, 2012). However, during the interviews, staff still reported time barriers. Other factors may influence staff availability, including staff shortage and COVID-19. Alternatively, staff may have considered PAMI-UK a structured intervention requiring significant time and planning. During reflective sessions, staff reported not implementing the intervention due to time. However, they proceeded to discuss engaging in multiple musical interactions suggesting that the small interactions are not considered PAMI-UK by staff. Although staff found it challenging to find available time, they reported that the benefits outweighed any potential additional time and workload pressures. Although PAMI-UK can be implemented into current practices, the training requires staff to attend multiple sessions, which staff found challenging to attend regularly due to availability, primarily if an emergency occurred just before the training.

#### 7.4.4 Staff Knowledge, Attributes, and Skills

Staff reported experiencing anxiety when initially exploring the manual as it looked too technical, and they felt they were not 'clever' enough. Staff doubting their own abilities have been highlighted in other research (Rapaport et al, 2017). Many staff demonstrated innately possessing the skills presented in the intervention but lacked the confidence or terminology, making the intervention appear daunting. Staff can find participating in intervention research daunting if they have not been involved in research before (Law & Ashworth 2022), this may have added to staff initial anxiety and feeling of not being 'clever' enough. Throughout the studies, the researchers aimed to reduce anxiety and promote confidence by highlighting the PAMI-UK principles, in particular, PAMI-UK being staff-experienced-led. Staff in care homes can experience a lack of recognition from society, management, and residents' relatives resulting in a lack of confidence in their abilities (Lawrence, 2016). Additionally, staff can feel that researchers will criticise their current practices, which explains why they are attempting to implement new interventions (Lawrence & Banerjee, 2010). In the PAMI-UK intervention, the researchers aimed to reduce anxiety and fear of criticism by recognising staff's abilities and acknowledging that the intervention aims to enhance their current practices and abilities, not criticise them. The PAMI-UK facilitators acknowledged the care staff as the experts creating a collaborative approach (Lawrence & Banerjee, 2010; Lawrence et al., 2012). This initial recognition and acknowledgement helped to develop a rapport between the care staff and the PAMI-UK facilitators. As the studies progressed, staff became more confident in the skills and terminology and felt a sense of pride in their abilities.

#### 7.4.5 Staff Engagement and Motivation

The relationships and interactions developed during PAMI-UK require additional time and effort for staff to become attuned and individualise interactions to residents' needs. Staff with a 'get the job done' mind-set may be less willing to incorporate PAMI-UK into their routines (Lawrence et al., 2016). The staff participants were motivated to learn the PAMI-UK skills, finding benefits during implementation that resulted in practice changes. However, participation was voluntary; therefore, they already intended to change. One staff member was concerned that the intervention

requiring staff motivation to learn, and change could make it challenging to implement with staff with a 'get the job done' mind-set. Early signs of staff resistance were displayed when participants attempted to encourage non-participating staff to use some of the skills, this resistance has also been observed in other research (Rapport et al., 2017). Previous research has suggested that if care homes have an insufficient learning climate, they are less likely to be open to change and therefore less likely to engage in the new intervention (Groot Kormelinck et al., 2020).

## 7.4.6 PAMI-UK as a Care Home Wide Intervention

During the studies, staff and residents participated as dyads, which staff felt they were able to manage. However, many participants were concerned that if PAMI-UK was introduced as a care home psychosocial intervention, they would not be able to upscale the intervention to include all residents. Staff felt that there was not enough time during a shift to provide the same effort, time, and attention to all residents that they had with their participating resident. Although staff were concerned about upscaling to a care-home-wide intervention if all staff were trained in the intervention there is more chance of sustained practices and potentially less work for staff as they would not be the only ones offering the intervention (Rapport et al., 2017)

The barriers and facilitators reported in these studies have been highlighted by other psychosocial intervention research (Kloos et al., 2020; Garrido et al., 2019, 2017). Some barriers could be reduced or eliminated if PAMI-UK was implemented in care homes as a care-home-wide intervention where all staff are trained in the skills (Garrido et al., 2020). In the two studies, residents did not receive daily PAMI-UK interactions on multiple occasions due to unavoidable circumstances where the staff member could not work with their resident due to sickness, different units, or working with other residents. If all staff were trained in the intervention, care homes could maintain consistency by the resident continuing to receive PAMI-UK interactions regardless of the staff member working with them. If PAMI-UK became a care-home-wide intervention, it could potentially change care home culture,

although this is outside the scope of this PhD. For PAMI-UK to be upscaled, there may be some practical considerations to ensure successful implementation, including methods to ensure that all staff know each resident's tailored plan and have easy access to residents' personalised playlists.

#### 7.4.7 Barriers to Implementing PAMI-UK Outside of the Research Context

While the two studies highlighted the barriers and facilitators that impacted the implementation of PAMI-UK during the study, it must also be noted and considered the potential barriers to implementing PAMI-UK outside the research context. While PAMI-UK aims to be a low-cost intervention, making music interventions accessible to a wider care home population, it could never be a no-cost intervention as there are costs involved with running person-led training. However, this cost would only be attributed to the initial staff training; once staff were trained in PAMI-UK, there would be no continuous costs to using the skills in the care home. If PAMI-UK was to be developed to run outside of the research context, a core team of PAMI-UK facilitators would provide the training and reflective sessions to care homes. Either one or two facilitators run the initial training, with at least one facilitator being a registered music therapist. In PAMI-UK, the music therapist is a member of the PAMI-UK team. Whereas for PAMI-DK, care homes would need to employ a PAMI-DK-trained music therapist. Changing the facilitator delivery could reduce some costs as the care home would potentially pay a one-off payment rather than a regular music therapist's salary. Either way, the PAMI-UK facilitators' salaries would need to be paid if PAMI-UK was provided outside of a research context.

When presenting PAMI-UK to the music therapy community during the PhD, discussions have arisen over whether PAMI-UK would be a commercial training package that care homes could purchase or whether it should be a mandatory training embedded into the care system. As mentioned earlier, there are no mandatory requirements for specific accredited care staff training (Smith, 2019). The areas of training that care homes must cover to meet CQC guidelines only focus on physical health and safety. Therefore, having PAMI-UK as a mandatory training would require substantial changes to the social care system and policies. Whether PAMI-UK

was commercial or mandatory, the cost of providing the training to staff would be the responsibility of the care home (Blane, 2023). The cost of training has been highlighted in several studies as a barrier. However, it has been argued that if care homes invested in training the staff they have, the cost of the training would outweigh the costs of continuing to recruit staff when staff leave due to the lack of staff development (Jack et al., 2019). If PAMI-UK was a training that care homes purchased, the training might still be limited to the same care homes currently prioritising funds for psychosocial interventions and, therefore, not making it more accessible.

Care homes must have a sufficient number of suitably qualified, competent, skilled, and experienced staff members on each shift to meet the needs and care of residents, which is in accordance with current legislation (CQC, 2023). Therefore, when staff are required to complete training, managers are required to ensure that a sufficient number of staff are still available to care for the residents. There are no policies or guidelines on when care staff should complete training and whether they are paid for their time. If managers schedule training during the individual's shift, there is a cost attached to needing to rota more staff to work that shift to maintain a sufficient staff level. The other alternative is for staff to complete the training during days off, as seen in the PAMI-UK studies and Melhuish et al. (2017). In this case, the staff are completing work and not being paid for their time. This scenario highlights a significant issue of the UK care system that has been highlighted several times already: care staff are unpaid and underappreciated (Lawrence et al., 2016; Kadri et al., 2018). Not paying staff to complete training can make them less motivated and willing to complete training and unlikely to change their practices (Huda, 1996; Surr et al., 2020).

Another barrier to implementing PAMI-UK outside of the research context is the retention rates of care staff. The high turnover rates are well-known (Randell, 2021), which was also highlighted in the PAMI-UK studies when many staff withdrew from the study due to leaving their job at the participating care home. The high turnover

rates result in high rates of new staff being recruited, which can impact the implementation of interventions (Woltmann et al., 2008; Damery et al., 2021). As mentioned previously and in other research, training is best implemented as a carehome-wide intervention, with all staff being trained to reduce potential barriers and improve consistency (Clelland et al., 2005). However, the high turnover rate means that, at times, it is likely that some staff would be untrained in PAMI-UK. If care homes decide to refrain from training new staff in the techniques, barriers to implementation could appear. Alternatively, there could be a continuous cost for care homes to provide regular PAMI-UK training to ensure all staff are trained.

As mentioned in Chapter One, care homes can be owned privately, by charities, the NHS, or the Local Authority, with the homes either running for- or not-for-profit. Care home placements are either self-funded or funded by local authorities, the NHS, or other organisations. Each care home decides how many authority-funded placements they offer and the cost of resident fees. These differences in care homes result in substantial variations in practices, priorities, and quality of care, creating the fragmented and uneven-natured social care system discussed in Chapter One (Bach-Mortensen, 2019; Walker et al., 2022). The variations between care homes could impact not only the implementation of PAMI-UK within the care home but also the likelihood of certain care homes engaging with PAMI-UK. For PAMI-UK to work within the UK care system, there is a need for a change in the care home culture. More funding to support psychosocial interventions is needed, which would require owners and managers to change their priorities away from profitability and towards the needs of the residents (Kellett et al., 2016).

Additionally, there would need to be a change to the staff's working conditions, with care staff being valued for their work and attributes. Staff would need to be given more autonomy in embedding the learnt skills as this could foster a learning culture, increasing staff motivation and engagement with training such as PAMI-UK (Huda, 1996; Booth et al., 2005). Finally, there is a need to move towards person-centred and relationship-centred theories being translated into practices with attitudes

changing towards residents to see them as equal partners in the relationships and to recognise that it is okay for care staff to become emotionally invested in their residents. With the current care home culture and system, PAMI-UK will still only be available to the care homes that can offer psychosocial interventions due to their available funds and priorities around meeting residents' psychosocial needs. As this thesis documents the early stages of the PAMI-UK development process, more development is needed. In future development stages, the researchers should consider more thoroughly how the intervention would work outside of the research context to ensure that the intervention is fit for purpose.

# 7.5 Maintaining and Evaluating the Quality and Fidelity of PAMI-UK

#### 7.5.1 Maintaining the quality and fidelity of implementation of PAMI-UK

As mentioned, conducting the studies remotely made it difficult to determine whether staff implemented PAMI-UK skills or music more generally. Being unable to determine the quality and fidelity could mean that PAMI-UK was being implemented incorrectly or inconsistently across care homes and care staff. Several methods can be used to ensure that quality and fidelity are maintained. A fidelity checklist is one method researchers use; the checklist lists intervention components which are ticked off if delivered (Powers et al., 2022; Walton et al., 2020; Breitenstein et al., 2010). There are several reasons why a fidelity checklist may not be suitable for PAMI-UK. Previous research has highlighted that there can be tension when researchers attend care homes with new interventions, as staff view this as a criticism of their current work (Lawrence et al., 2016; Cooke, 2018). If a fidelity checklist was used, staff may feel like they are being tested, which could cause the tension highlighted in previous research. However, previous research has suggested that a self-review checklist, could help evaluate and maintain fidelity while reducing the risk of staff feeling tested (Sprange et al., 2021).

Additionally, the core principle of PAMI-UK is person-centred. Therefore, it is key that the PAMI-UK skills are embedded into daily social interactions rather than being a structured session. As PAMI-UK is not structured, a fidelity checklist may be unsuitable as the same components would not be used in every interaction or with

every resident as the skills are tailored to each resident's needs. Additionally, it would be challenging to observe a sufficient number of interactions to have an indepth evaluation of fidelity. There has been a significant amount of discussion around the possibility of fidelity and adaptability. Perez et al. (2016) proposed a modified Carroll et al.'s (2007) framework that enables fidelity evaluation while allowing for adaptability within an intervention. Future research could consider using the modified Carroll's framework to evaluate and maintain the fidelity of PAMI-UK.

In the original study design, regular observations of staff using the skills in practice were planned, which would have allowed the researchers to evaluate the quality and fidelity of PAMI-UK. In future research, having regular observation sessions which are filmed would ensure that all staff are offering the same quality PAMI-UK skills to residents. However, this could cause anxiety about being observed, which could impact the delivery of the intervention (Sprange et al., 2021). Previous research has suggested that if facilitator shadowing is offered, as initially planned in the PAMI-UK studies, and used in PAMI-DK, this could improve fidelity (Sprange et al., 2021).

The two studies only documented the implementation of PAMI-UK until the reflective sessions finished; therefore, there is no research exploring the implementation of PAMI-UK after formal training is withdrawn. There are several ways that the quality and fidelity of PAMI-UK could be maintained after training, which future research should consider and explore in future studies. The most structured form of maintenance would be to offer a follow-up review session several weeks or months after the training ends to review the care home's progress and ability to continue implementing PAMI-UK. The session would allow the PAMI-UK facilitator to provide further guidance but would require additional time from the care home and the PAMI-UK team. Another method is to offer a forum for teams trained in PAMI-UK to support each other, allowing individuals to discuss challenging areas and gain ideas and advice from other care homes. Thirdly, the PAMI-UK team should encourage care home managers to include PAMI-UK in formal supervision to allow staff to reflect on their use of PAMI to maintain quality and fidelity.

Several outcome measures should be measured when evaluating the PAMI-UK intervention. Through observations and diary entries, the researchers should evaluate the implementation of the PAMI-UK components. These methods would highlight the consistency of skills delivered, the number of times PAMI-UK is implemented, and the care staff's comprehension. Residents' engagement with PAMI-UK should also be evaluated, with their and their family's views on the intervention being collected. The retention of both staff and residents should be collected. These outcomes would help evaluate the quality and fidelity of PAMI-UK implemented in care homes and evaluate the acceptance of the intervention by both staff and residents.

#### 7.5.2 Maintaining the Quality and Fidelity of PAMI-UK Training

For the two studies, there were only two PAMI-UK facilitators who were involved in all training elements, therefore, the quality and fidelity of the training was maintained. However, if PAMI-UK was delivered outside the research context, multiple PAMI-UK facilitators would be needed. Therefore, the quality and fidelity of the training may not be maintained. A facilitator's manual could be developed outlining the delivery of training to ensure high-quality and consistent training regardless of the PAMI-UK facilitator (Carroll et al., 2007; Perez et al., 2016). Additionally, training sessions could be recorded and evaluated for fidelity (Sprange et al., 2021).

# 7.6 COVID-19 Impact on the Project

## 7.6.1 Challenges of COVID-19

The original study design still consisted of three main elements: the development of a culturally appropriate UK version of PAMI, then a manual field-testing and evaluation study to explore the intervention in care homes. However, the design and aims changed due to COVID-19 (Appendix 5). At the pandemic's start, the researchers reassessed the study design, documenting areas unable to occur under the government guidelines. The primary researcher assessed alternative methods by reviewing their strengths and limitations. A study design was developed that could

continue under COVID-19 restrictions while aiming to maintain a robust study design. Due to the restrictions, there are methodological limitations which would have been absent in the original design. COVID-19 significantly impacted the care homes in the study which subsequently influenced the intervention and running of the study. During the two studies 19 different lockdowns occurred across the seven care homes resulting in staff being unable to attend reflective sessions due to them testing positive and documents could not be collected during lockdowns. During the studies the COVID-19 guidelines including isolation when testing positive for COVID-19 impacted the studies, at one point there was large number of postal staff isolating resulting in delays in postal services, as a result it was taking longer to get the required documents to care homes, delaying the study start date for many care homes.

During development, the researchers aimed to involve care homes in expert consultations to ensure that the manual was suitable for care staff. The consultations remained in the updated design; however, they occurred remotely. The researchers had reduced access to care homes due to organisations shutting or diverting their focus to COVID-19 research; therefore, staff were found through the research team's contacts, particularly Facebook forums for activity coordinators. When staff involvement was scheduled, staff were experiencing high stress levels due to lack of Personal Protective Equipment (PPE), high COVID-19 rates, and uncertainty; therefore, questionnaires were used to reduce additional stress and burden. Although insightful feedback was provided, staff had less input into the PAMI-UK development due to the changes.

The original study design aimed to have all elements in-person, with the primary researcher attending care homes, from recruitment through to the final interview. The researcher aimed to develop a relationship with the care homes, residents, and staff to ensure the study and intervention worked for each individual. Instead, all elements were completed remotely with in-person support from an In-Reach Practitioner. The remote study design potentially resulted in increased missed

reflective sessions, increased missing data, and a lower document return rate. The researchers had no direct contact with residents resulting in them having less active engagement. Initially, the researchers planned to conduct resident interviews, a recommendation from the systematic review (Chapter 2); however, it was felt that remote interviews would have been challenging for residents. Instead, a resident questionnaire was created to capture residents' experience; however, there was a misunderstanding with staff completing the questionnaire based on their experience rather than working with residents to complete it.

All data collected was self-reported; therefore, it is difficult to determine whether staff implemented PAMI-UK correctly. Additionally, the researchers could only monitor the running of the study remotely; therefore, they relied on staff to report issues during the reflective sessions. The researchers planned to conduct in-person monitoring sessions, with the researcher observing staff interacting with residents. Some staff interactions would have been recorded during these sessions as a data collection method. When converting to remote delivery, reflective sessions were introduced as a substitute for the observations. However, these were not direct substitutions; the PAMI-UK facilitators could only provide feedback on the information provided by staff. As the facilitators had no direct contact with the residents, the ability to tailor guidance to the individual resident was limited.

The quantitative outcome measures used were changed for the second study because the initial measures required a researcher to administer the questionnaires. Instead, questionnaires were used that could be sent via post to be completed in the participants' own time. Some replacement questionnaires may not have been the most suitable measure for the intended outcomes. For example, staff struggled to understand the M-NCAS instructions resulting in many of the staff members completing the measure incorrectly. Having staff complete the questionnaires independently without the researcher's guidance could have resulted in a low return rate, missing data, and incorrect completion due to staff being unable to ask for immediate help. Additionally, some outcome measures, such as the Verbal and non-

verbal Interaction Scale, were removed with the researchers being unable to find a suitable alternative.

# 7.6.2 Positive Outcomes of Conducting the PAMI-UK Study During the COVID-19 Pandemic

Although the pandemic created challenges resulting in significant changes to the study design, it also resulted in some changes to the project and intervention which would not have occurred within the original study design. As the study was completed remotely, the research team could create international collaborations with a music therapist researcher (BS) in the United States. As the PhD student was a non-music therapist, it was decided that although they would facilitate the webinars, the reflective session would be facilitated by BS, enabling staff to gain knowledge from a music therapist. BS's experience and knowledge as a music therapist and researcher contributed to developing the PAMI-UK manual and project, which was only possible because the project was remote.

Additionally, the pandemic resulted in an In-Reach Practitioner from Lincolnshire NHS Trust joining the study (RF). Initially, the project planned to recruit Nottinghamshire care homes through care home organisations in the county. However, when the organisations diverted attention towards COVID-19 research, the researchers developed a collaboration with the Lincolnshire NHS Trust which consisted of research delivery support from an In-Reach Practitioner. As part of the In-Reach Practitioner's role, she completed recruitment, consent, capacity assessments, managed data collection, and liaised with care homes to support the research delivery. As an NHS employee, she could attend care homes throughout the pandemic. Additionally, the care homes belonged to the In-Reach program; therefore, a relationship between the care homes and RF was developed prior to the project. The In-Reach Practitioner could advise on suitable care homes and encourage them to participate.

Although this project was not COVID-19 research, staff reported the intervention as valuable during times of uncertainty and stress. The intervention allowed staff to

incorporate meaningful activities and interactions when many activities had to stop due to being facilitated by external organisations. Many residents deteriorated due to limited care home access to families and visitors. Many individuals became socially isolated and withdrew from the care home community due to anxiety and fear about COVID-19 (Alzheimer's Society, 2020; Gordon et al., 2020; Velayudhan et al., 2020). PAMI-UK provided staff with a tool to engage with these residents 1:1 and encourage them slowly to integrate back into the care home community to reduce social isolation.

## 7.7 Final Manual Recommendation

### 7.7.1 Manual Format

Carers require a portable manual with easy to access information. For some carers, the paper manual was unsuitable for their role, with the design being more suited to desk jobs. Additionally, many struggled to comprehend the information. As technology develops, manuals no longer need to use only written text. A web- or app-based manual would allow audio and videos to demonstrate skills (Anderson-Ingstrup, 2020). However, only offering a web-based manual could prevent individuals who are technologically illiterate from engaging. Additionally, care homes may lack multiple devices to enable multiple staff to access the manual simultaneously. Therefore, the manual should be available in paper- and technology-based formats to ensure suitability for all staff.

## 7.7.2 Training Delivery

While the studies highlight the plausibility of remote delivery, a complete remote training format may not be the most suitable. Staff were divided on in-person vs online training. Whilst the initial training could continue to be delivered online, potentially to multiple care homes together, an in-person shadowing element should be added, where staff can observe the PAMI-UK facilitator implementing the skills, and the facilitator can observe the staff's attempts. This element would allow staff to gain more tailored guidance on implementing the skills with their resident. Additionally, the PAMI-UK facilitator could determine whether staff are implementing specific PAMI-UK skills and the quality of implementation. The in-

person shadowing could be in addition to or instead of the reflective sessions. However, the PAMI-UK facilitators must consider staff availability if the shadowing was in addition to the current elements.

# 7.8 Methodological Difficulties, Limitations, and Recommendations7.8.1 Researching in Care Homes

Conducting research in care homes is challenging. The researchers reviewed previous care home research while developing the study methodology to ensure that the proposed research was suitable for care home settings and limited the amount of additional work and time required from staff (Forggart et al., 2007; Goodman et al., 2011; Luff et al., 2011). However, COVID-19 introduced new methodology challenges. Researchers' flexibility is vital in all care home research; however, it was essential whilst care homes experienced COVID-19 and attempted to manage the challenges related to the pandemic. During the research, many care homes experienced multiple COVID-19 cases for both staff and residents that led to either units or whole care homes going into lockdown until testing negative. The care home lockdowns and COVID-19 positive participants affected the research activities and as a result have potentially affected the results.

During lockdowns, the In-Reach Practitioner could not attend the care home. Staff had increased work pressures to prevent the spread of the disease and some participating staff and residents were separated by different units during the lockdowns, preventing the staff from using PAMI-UK with the resident. If resident participants were COVID-19 positive, contact was reduced to essential care. All these challenges resulted in missed reflective sessions, reduced PAMI-UK interactions documented, and staff using PAMI-UK with non-participating residents to compensate.

Involving individuals with dementia requires the researchers to have sufficient experience and skills to support individuals whose impairments may make participating challenging (Luff et al., 2011). The researchers all have experience

working and communicating with individuals with dementia from previous jobs in care homes, ensuring they had sufficient skills to support the residents in the study. However, due to being unable to attend care homes the amount of support the researchers could provide residents was limited, the researchers relied on staff to report any distress or withdrawal. Additionally, it was difficult for residents to communicate with the researchers, especially without assistance from staff. Interest and consent sheets were provided to care homes to allow residents to communicate sensitive or confidential information without the assistance from staff. No sheets were returned, however due to the researchers being unable to attend the care homes it difficult to determine if the residents did not have any questions or concerns or if they were not provided the opportunity to complete the sheets.

Previous research (Luff et al., 2011) suggests spending time in the care home prior to the study helps develop a rapport and good communication with the care home and staff. Visiting the care homes prior can also help the researchers understand the care culture, which could influence the research. Due to COVID-19, the researchers were unable to attend care homes. Being unable to attend the care homes could have influenced staff motivation, staff drop out, and their comprehension of the study and intervention which subsequently could influence the results. The researchers hoped that having the In-Reach Practitioner complete recruitment and consent in-person could account for the researchers' inability to attend, however it was not an equal substitute with some elements of the study being influenced by the remote format. The researchers required the care staff or manager to introduce eligible residents to the study to protect residents' privacy. Therefore, in many cases, the manager and care staff determine who were appropriate participants, even if the researchers aimed for participants to be representative of the population (Luff et al. 2011).

#### 7.8.2 Retention Rate and Missing Data

The study aimed to investigate the appropriateness of the outcome measures for future research. However, the two studies had a high dropout rate and a low questionnaire return rate. Posting documents was used to overcome the challenges

of care home COVID-19 restrictions; however, ensuring that staff returned the documents and completed them accurately was challenging, despite the research team continuously contacting care homes for them. For documents that were returned, there were high rates of missing data. Additionally, some staff returned documents several months post-study; therefore, it is difficult to determine whether the staff completed the documents at the appropriate time points, potentially misrepresenting the outcomes.

While attending in-person to complete outcome measures with staff would be the ideal method, when researchers could not attend care homes, completing the questionnaires with staff by phone would have been a more suitable substitution. Completing the outcome measure with staff via phone would have also enabled researcher-led outcome measures, including the Professional Care Team Burden (PCTB) scale (Auer et al., 2015) and Verbal and Non-verbal Interaction Scale (Williams et al., 2017), scales the researchers originally planned to use which may have been more suitable than the selected outcome measure.

Although promising, the small document return rate and high volumes of missing data limits the validity of extrapolating the outcomes of this study, i.e., whether similar positive outcomes of PAMI-UK intervention would occur in repeated or wider studies. Future research should consider the alternative formats for collecting data to improve return rates and missing data.

#### 7.8.3 Collecting Data as Dyads

Some staff felt that the researchers missed recording vital opportunities by restricting data collection to one resident. Staff began using the skills with non-participating residents, once observing the benefits. Although staff mentioned other residents in the reflective sessions, the reflective prompt sheets and diary entries only documented the participating resident, which staff felt led to missed opportunities.

Some staff reported documenting other non-participating residents on their forms, especially when their participating resident presented minimal engagement. Therefore, it is difficult to determine whether all results presented are from participating residents. Additionally, it is difficult to determine in reflective sessions when staff are discussing their participating resident and when they are discussing non-participating residents.

### 7.8.4 Residents' Involvement

The systematic review (Chapter 2) highlighted that in most music care home research, residents are passive participants with little opportunity to share their opinion or experience. In the PAMI-UK studies, a resident post-intervention questionnaire was introduced to enable residents to share their perspectives without requiring researchers to attend the care home. However, when the questionnaires were returned, they seemed to document the staff's experience rather than that of the residents.

Interviews are suitable if adapted appropriately to accommodate the individual with dementia's needs, with the researchers first developing a relationship to ensure residents are comfortable. (Shannon et al., 2021; Cridland et al., 2016). Enabling residents with dementia to actively participate in research can be valuable as it enables them to continue contributing to society (Cridland et al., 2016), an element highlighted by Kitwood's emotional needs flower to enable individuals to maintain their personhood (Kitwood, 1997). Future research should aim to use the alternative methods to obtain residents' perspectives.

### 7.9 Clinical Implication

This doctoral study reiterates the importance of staff training in care home. Although staff may have the skills and abilities, they may lack the confidence and terminology, as highlighted by staff who used PAMI-UK-like skills pre-PAMI-UK. Additionally, they may be discouraged from using skills focusing on residents' psychological, social, and emotional needs as these are seen as taking time away from caring for residents'

physical needs. The PAMI-UK training raises awareness for care staff and management, highlighting the equal importance of attending to residents' psychological, social, emotional, and physical needs. The PAMI-UK intervention provides staff with the skills and knowledge to embed musical interactions into daily routines that promote attunement and person-centred care, potentially improving reciprocal interactions enabling residents with dementia to be equally active partners in interactions.

Currently, care homes provide limited music and art interventions, potentially due to limited time, knowledge, and resources. Embedded PAMI-UK into current routines may potentially reduce the barriers of time and workload pressures to ensure that staff are implementing high-quality music interventions that can benefit staff, residents, and the overall care home.

This doctoral study is the first project to investigate the implementation of PAMI remotely. Although the research suggests that in-person elements are most suitable, the research highlighted the plausibility of running the training remotely when necessary. For the project, it was due to the COVID-19 pandemic; however, providing remote training opportunities increases the accessibility of the training for care homes that may be limited due to their geographic location.

## 7.10 Future Research

Deciding to change the intervention delivery by not having music therapist training care staff was made due to the limited access of music therapist in most care homes. Although two music therapists were on the research team, with one facilitating the reflective sessions, the Danish team were concerned with the change. Although similar results are reported from both research teams, future research may wish to compare the two intervention structures to determine whether they are of equivalent quality. For example, to determine whether having a non-music therapist facilitator and remote training influences the effectiveness and efficacy. However, this research would still need to consider cultural differences between the two

countries; otherwise, cultural factors may influence the results, such as care home ownership and heterogeneity in care home standards.

The PAMI-UK intervention was developed to offer a cost-effective alternative for care homes unable to employ music therapists, enabling music interventions to be widely accessible to a broader care home population. Although there is no cost related to implementing PAMI-UK, there would be costs around running the training. i.e., paying the PAMI-UK facilitator. Therefore, future research should complete a cost analysis to determine whether the intervention is a cost-effective alternative.

Staff received supervision throughout the study through fortnightly reflective sessions, which motivated staff to continue implementation to ensure they had sufficient material to discuss. For benefits to continue, staff are required to provide daily regular musical interactions as music's impact generally only persists during or immediately after the use of the intervention. Therefore, research is needed to investigate whether staff would continue incorporating PAMI-UK when the reflective sessions finish. Future studies could repeat the current study design but complete at least one more data collection time-point, several months after the reflective sessions end to determine whether staff have continued to use PAMI-UK and to determine whether behaviour and mood changes remain. Additionally, future research may wish to conduct follow-up interviews to gain a greater understanding of staff experience and views of implementing PAMI-UK once formal supervision ends. However due to high staff turnover rates this may not be feasible with all participants.

Future research may wish to explore whether the PAMI-UK training could be provided to non-formal family caregivers to support them when caring for a relative with dementia. Family caregivers received even less training and support than care home staff and, therefore, the PAMI-UK training could give them the support, knowledge, and confidence to continue interacting with their relative with dementia with potential benefits for both the caregiver and individual with dementia.

Additionally, for many family caregivers, in comparison to care staff, becoming a carer is not a choice, it is a responsibility that is unexpectedly placed upon them when their family member is diagnosed, and therefore, they may not have the same innate skills and attributed demonstrated by the staff in the studies. It would be interesting for future research to explore whether PAMI-UK can be learnt and implemented by non-formal caregivers.

### 7.11 Conclusion

This doctoral study developed, piloted, and evaluated PAMI-UK to encourage care home staff to further develop their non-verbal communication skills when working with people with moderate to advanced dementia. The studies add to the growing evidence for the benefits of care home music to facilitate social interactions between residents with dementia and care staff. Music is an accessible communication form for people with dementia that facilitates social interactions through reducing some behavioural and psychological symptoms. Music helps to orient people to the present and helps individuals to maintain an identity allowing them to be equal and active partners in interactions. Previous research has explored music to facilitate social interactions, however, many have low methodology quality and barriers including time restrictions which prevents successful implementation. PAMI is an evidence-based staff training intervention that aims to provide care staff with the skills to embed musical interactions into current routines, enabling staff-resident interactions that use a communication form accessible to residents without increasing staff stress or burden.

Through a systematic review and staff expert consultations the researchers highlighted the significant changes required to ensure suitability, appropriateness, and usability, including altering the training length, delivery, and structure. At the beginning of the manual development stage the start of the COVID-19 pandemic resulted in the researcher not only adapting the intervention to be appropriate for UK care homes but also developing an intervention that adhered to the COVID-19 national restrictions. PAMI-UK was converted to a complete remote training tool

leading to unforeseen changes and challenges. Although it was feasible to deliver PAMI-UK remotely the results imply that some elements are lost, and therefore, a hybrid of in-person and remote training may be more suitable. Despite the need for significant changes, PAMI-UK has aimed to keep the core PAMI principles, including person-centred, experience-led, and the ethos that PAMI is a concept that cannot be taught, instead staff must discover it through reflection and exploratory practices.

Although the PAMI-UK interventions aimed to address the barriers highlighted in previous music interventions the staff highlighted several barriers that influenced implementation including time restraints, other staff's attitudes, and staff sickness. By incorporating PAMI-UK into care homes as a care-home-wide intervention where all staff undertake training, barriers could be reduced or eliminated and ensure consistency across staff members. Introducing PAMI-UK as a care-home-wide intervention has the potential to change care home culture to ensure that personcentred care is embedded into residents' daily lives rather than only being theoretical. Future research should consider exploring PAMI-UK's potential for changing care home culture. The COVID-19 pandemic resulted in several methodological limitations including high dropout rates and missing data, owing to the researchers being unable to attend care homes. Future research should address the methodological issues highlighted in this thesis including online delivery, dropout rates, and lack of persons with dementia perspectives. This doctoral study presents promising results for the use of PAMI-UK in care home to improve social interactions, therefore, future research is needed to continue to evaluate the adapted PAMI-UK intervention.

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### 8. Appendixes

Appendix 1 Facebook Posts Advertising Expert Consultations with Care Staff

Q Search Facebook	ŵ	Image: A start of the start			÷.•)		 0	
Search results in Care Home Activity Co-Ordinators		Bryony V 6 May 202 Hi delete if not a	0 · 😁	9 working as an a	ctivity coordinator ir	•••• n a care home. While		
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Filters Posts you've seen		be working with care homes and	care homes to gain what staff would wa	a better understa ant to see from th	anding of how my in e product. Covid ha	dents. Currently I should Itervention could work in s stopped this so if any Id love to get feedback		
Most recent			o have experience w			43 comments		
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Tagged location 🔍		Bryony V 22 July 202		ile in the group: <b>C</b>	are Home Activity (	Co-Ordinators.		
Date posted		Hi, delete if not a working I notice were not express leaving my job a aims to improve months asking fi enable me to co throughout the p being involved p	allowed. I spent 201 d how undervalued sed, I had a constan ind taking up the of interaction and rela or peoples feedback ntinue without goin project to make it a:	activities are. The t battle with care fer of a PhD posit ationships betwee c. As COVID contin g in to care home s suitable for care mplete the attache	importance and ess assistance and man- ion to work on a new n care staff and resi- nues I am having to ess. Our aim is to invo- homes as possible. ed questionnaire am	n a care home. While sentialness of activities agement. This led to me w music intervention that dents. I posted several change by the project to olve members of staff If you are interested in d return it to me to		
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### Appendix 2 Expert Consultation Questions

PAMI-Person Attuned Musical Interactions

PAMI is a Danish intervention developed by a group of music therapist and researchers to be used by members of staff in care homes. The intervention consists of training and a manual with the principal values and techniques for staff to use. PAMI' takes music therapy skills and adapts them to be appropriate for staff to use in their daily routine and interactions with residents, to ensure that the benefits of music therapy is available to all care homes rather than just those that have the fund to employ music therapist. The training will teach staff to use their voice in a musically way to interact with residents, this will include changing elements of their voice in relation to the emotional state of residents and using songs to regulate emotional state and develop relationships. The manual will also teach staff how to use music and sing during personal care to provide more relaxing and productive personal care. Finally the manual will help staff to assess sounds in the care home environment and how sounds can be reduced or changed to improve the experience for residents. My research is to take the PAMI manual that the Danish team produced and redesign it to be appropriate for UK care homes. I can't really provide much more information than that as I am currently in the development stage of the manual. But I'm really keen to get the involvement of staff who work in care homes at an early stage so that I can produce a intervention that staff will actually use and will work. Any comment you have on the Intervention or Study design I would greatly appreciate hearing.

PAMI Manual development

What is your job role in the care home?

1. What are your views on using music in care?

2. Would you feel comfortable using you voice and music in your role? If not what would make you feel more comfortable?

3. Would you want a section on singing skills to make you feel more comfortable with using your voice ?

4. In your care home do care staff members get involved with activities?

5. What kind of activities do you currently have in your care home? If you use music what kind of music activities do you provide?

6. Do care staff members have 'meaningful' interactions with residents that aren't task orientated? IF not what could be done to improve this?

7. What would be the best format/layout for the manual to be presented in ? For example, paper form, Digital?

8. To work in your care home what is the best way to provide training? For example, interactive, Computer based, group session?

9. How long should training be? For example one day?

10. Is management positive/ supportive about activities?

11. What would be the best way to ensure the intervention would be successful in your care home?

12. What's the best way to get staff and management on board?

13. How did the pandemic affect the activities provided to residents?

14. How did the pandemic affect the interactions between care staff and residents?

15. Any other information on how the pandemic affected caring for residents or how the pandemic affected your job in the care home?

#### Study Design

Due to COVID my study design has had to change with the study being moved online.

16. In research we would call my project a intervention, in research I've read that care staff don't like the term intervention, what do you think the best way is to describe my project so it is accepted by staff?

17. How do you feel a intervention like this could be implemented in to the care home daily routine?

18. Would you prefer to have training that is already produced and is completed in your own time or training provided over a video conference call?

19. Does you can home use technology/ internet within routines?

20. In your care home would you have the ability to use video conference call platforms (zoom,teams, skype) to complete training and interviews?

21. I am looking at running my study for 4 months what would keep staff members motivated to use PAMI for this long?

22. If you have any other feedback or problems I need to consider in relation to music, activities or how this type of training and manual would work in you care home I would really like to hear them.

### Appendix 3 Manual Content Table

Section name	Theory	Skills	activities
introduction	<ul> <li>Introduction</li> <li>How to use PAMI</li> <li>Principles of PAMI</li> <li>Care staff attributes</li> </ul>		
Communication	<ul> <li>Language impairments in people with dementia</li> <li>Types of communication</li> <li>Staff resident interactions</li> <li>Research on care home interactions</li> </ul>		<ul> <li>What is important in communication</li> <li>Current interactions with residents</li> <li>Good non-verbal communication</li> </ul>
Music	<ul> <li>Highlight the therapeutic benefits of music</li> <li>Research on music in dementia care</li> <li>Psychosocial model of music in dementia</li> <li>Music therapy/music activities</li> </ul>		<ul> <li>What music means to you</li> <li>Music in your own life</li> <li>Your relationships with music</li> <li>Using music in the care home</li> </ul>
The PAMI concept	Overview of the PAMI concept how each element connects		
The voice	<ul> <li>The musical parameters of the voice- tone, volume, rhythm, pitch</li> <li>Communicative musicality</li> </ul>		<ul> <li>Using your voice in a day</li> <li>How you use your voice</li> <li>Musical elements to your voice</li> </ul>

			<ul> <li>Musical elements in a resident's voice</li> </ul>
Framing	<ul> <li>Noise environment</li> <li>Assessing the environment</li> <li>Sense perception</li> <li>Sensory impressions</li> <li>Creating a safe environment</li> <li>Security and predictability</li> <li>Musical cueing</li> <li>Songs for cueing</li> </ul>	<ul> <li>Music to cue to tasks and times</li> <li>Creating a safe environment</li> <li>Assessing the sound environment</li> <li>Designing a sound environment</li> </ul>	Creating a safe environment
Balancing	<ul> <li>Residents' arousal states</li> <li>Songs for arousal</li> <li>Staff arousal</li> </ul>	<ul> <li>Arousal regulation</li> <li>Regulating your voice</li> <li>Waking a resident in the morning</li> <li>Bedtime</li> <li>Music to motivate movement</li> <li>Arousal control with song</li> </ul>	<ul> <li>Experience with arousal</li> <li>Musical arousal demonstration</li> <li>Song for different degrees of arousal</li> </ul>
Connecting	<ul> <li>Interacting meaningfully</li> <li>Person-centred care</li> <li>Personhood</li> <li>Holding</li> <li>Validation</li> <li>Attunement</li> <li>Social interactions between residents</li> <li>Group music activities</li> </ul>	<ul> <li>Centring for holding</li> <li>Songs with expression</li> <li>Group reminiscence</li> <li>Type of group music activities</li> <li>Music reminiscence</li> <li>PAMI music plan</li> </ul>	<ul> <li>Attunement, Holding, validation</li> </ul>

#### How to Use PAMI PAMI consists of four parts: This paper manual webinar The manual consists of PAMI's theory, exercises to help with reflection, practical skills and examples of using the A series of videos skills in routines. The manual has been colour coordinated to help recognise which of the elements the Fortnightly reflective box refers to. Boxes edged in yellow provided exercises; these are tasks to be completed during the webinar to help with reflection. Boxes edged in grey are practical skills that can be used with residents ٦-Boxes edged in blue are examples of how practical skills can be incorporated into daily routines Boxes coloured in grey are important information -Boxes coloured in yellow are summary -There is a lot of information in the manual. The information in the grey- and yellow-

coloured boxes is essential; make sure you read these sections. The remaining text provides care staff with additional information if they would like to learn more about communication and music. This can be read in your own leisure.

The interactive group training webinar will last approximately 3 hours and take place on Microsoft teams at a convenient time for the group members. During the training, you will discover more about PAMI and the skills provided in this manual. You will also complete the manual exercises through discussion with other members of the training and facilitator.

Videos are also available for you to refer to at any time. The videos consist of () both who have experience working with people with dementia in care. The videos present how the skills provided in training can be used in practice with a resident.

As part of the PAMI tool, fortnightly reflective sessions are provided. Reflective sessions provide staff with time to explore their interactions with other group members. Discuss what is working and set goals for areas to explore further.



### **CARE STAFF**

There are a range of different individuals required in care homes to ensure the safety and care of residents, whether they have dementia or not. However, for individuals with dementia, more assistance and care may be required due to impairments limiting their ability to complete tasks. Although all staff in care homes play a vital role in the care of residents, PAMI wants to specifically focus on carers and activity coordinators, as these two groups generally have the most resident contact.

Each care home is different; however, when care staff have been interviewed in the past, they felt, in general, they are undervalued and unappreciated by the care home, relatives of residents and the public. We wanted to use the beginning of this manual to recognise the amazing work of care staff. The role can be both physically and mentally demanding, requiring a range of qualities and skills that cannot be taught or learnt, such as empathy, compassion, dedication, and passion. We want to thank you for everything you do.

In previous research, care staff have been left feeling criticised for their current practices when researchers introduce new interventions. PAMI does not want to do this!! Many of you already have a range of amazing qualities required when working with residents with dementia. You may even subconsciously use the skills provided in this manual but without the terminology to communicate what you are doing. PAMI aims to guide staff who innately have these skills but may need the confidence to use them in practice or need a little support in how the skills can be introduced into different care areas. There may also be some staff who are not using these skills currently, and we hope this manual may provide them with the skills to ensure that residents can receive quality care from all staff. Including social activities and interactions can be extremely difficult when care homes exclusively priorities the physical health and safety of residents and you have little available time during shifts. PAMI will highlight how meaningful interactions can be introduced into routines without any additional stress.

Many interventions focus exclusively on the benefits for the individual with dementia, but PAMI aims to improve the experience for the staff and residents.

### Music

Music is a concept that is familiar to all of us. Music is not limited by age, culture, health, ability, or experience. Anyone can experience music without prior knowledge or education, making it an accessible and pleasurable activity enjoyed by many. Integrated into everyday life, whether individuals seek it or not, music is a powerful tool. Music can be experienced in various forms and situations, from actively choosing to listen to music, soundtracks in tv and films, and music being played in shops. A worldwide music census in 2019 reported that, on average, people spend 18 hours a week listening to music. Music is central to many people's lives, with the primary function being for enjoyment. However, music can be very therapeutic even for individuals with no previous training or therapeutic music experience.

When producing this manual, we asked the public the importance of music to them, below we have presented our results in a word cloud.



The word cloud highlights the range of reasons people use music, from concertation at work, managing emotions, and reminiscing. As you can see, many of the skills you will learn in this manual you may already do with your own music habits. We hope you can recognise these skills and discover how you can incorporate them into your work.

Although many people we spoke to said they could not live without music, we must remember that some people won't enjoy music as we found with one individual who found music irritated her.



### Exercise 10 - Musical elements to your Voice

For each musical element listed below think about where on the line you think your own voice would sit in everyday situations. Once you have done that, now using two different colours and complete the exercise again but think of A) when you are busy B) when trying to get a baby to sleep.



In the exercise above, you may notice that your voice changes depending on the context in different situations. This is usually done subconsciously without thinking. We can use this same idea when working with residents.

### > Exercise 11 - Residents voices

Now you have a better understanding of you own voice think about a resident you have a warm relationship with how does their voice sound. In a different coloured pen think about the voice of a resident you struggle to work with.



### Exercise 16- Attunement, Holding, Validation

Discuss your experience with Holding, Validation, Attunement. Do you do any of these already in your practise

#### Reminiscence

Music can evoke emotions and memories that allow residents to reminisce. The reminiscence of memories can allow individuals to maintain their identity from pre-diagnosis. As a staff member, aim to tune into the person's memories and internal resources.

Music can aid individuals to mirror moods, emotions, and experiences. It allows us to share the experience and recognise the other's feelings. Holding, Validation and Attunement can allow individuals to align to a person's memories and inner resources to create and strengthen relationships.

# Practical skill- Songs with expressions

Sing a familiar song in different ways, either expressed as emotions or as vitals. Try singing (choose example song). Now try singing the song again but change the emotion (sad, happy, angry, resigned) or vitality (hesitant, bouncing, lively, trailing, bubbling).

#### Social interactions between residents

When living in a community it is natural to want to interact with those you live with, this is the same for residents in care home with dementia. It is natural for residents to want to interact with other residents. Interactions with others will continue to contain similar elements including joking, practical jokes, flirtation, assisting others and hostility, staff should allow all of these types of interactions to occur. It can be challenging due to the differences in dementia severity and impairments however staff such encourage and enable resident-resident interactions to occur. Try to make the care home environment suitable to allow for interactions to occur without staff assistance (see section on Framing for more information on care home sound environment). Additional consider the layout of the care home does the seating allow for conversations to occur. When staff are talking with residents be aware of social cues from other residents that they may wish to join the conversation.



# Practical skills- Arousal regulation

When working with a resident with dementia aim to

Tune to the other person

Create space and structure

Remain in a balanced arousal

Use yourself to regulate

Before entering an interaction with an individual check in with your own emotions and arousal state. If you are in a state of anxiety or stress this will come across in your interaction and can affect the resident's emotional state

### Exercise 14- music arousal

https://www.youtube.com/watch?v=SRmCEGHt-Qk

Listen to this piece of music. Using the EIBA framework how does it make you feel? Does it change as the music changes?

Now think how this song may make you feel if you had low or High arousal. Do you think your feelings would be different?

# Practical skills- Regulating using your voice

Stimulating and sedating effects are obtained by musical parameters such as tempo, rhythm, timbre, volume, pitch, and timing. The exact technique used will depend on each individual. One individual may find lullables soothing which in a high arousal while for other it may agitate them further.

High arousal- try a soothing voice, slow tempo, smooth rocking movements, a certain distance and non-demanding attitude

Low arousal- try a vivid tempo, piercing voice, quick movements, touch, and emotionality



# Practical skills- waking a resident in the morning

When using music with a resident in the morning start with a quite song to ensure that the resident is not overstimulated. Using a gentle song to being with will allow residents to arousal slowly.

# Practical skills- bedtime

When using music with a resident at night use smooth soothing music to reduce resident's arousal slowly in preparation for sleep.

# Practical skills- Music to motivate movement.

Exercise one- ball game

Song- https://www.youtube.com/watch?v=nAQwygcfdPE

Arrange the residents in a circle with the facilitator in the middle. Throw the ball to individuals in turn. The facilitator should indicate to the individual whether the resident should be catching the ball or throwing it by acting out the action. This exercise can be done standing or sitting down.

Exercise two- marching

Song- Wish me luck https://www.youtube.com/watch?v=\_bGE8248N7Y

This exercise can be done either sitting or standing. Swing arms and lift feet in time to the music.

### Connecting

Connecting focuses on how music can be used with staff and residents to connect and interact more meaningfully. Interactions should be a mutually shared experience. This can be difficult with traditional communication due to some residents limited language ability; however, music allows residents and staff to be equal active parties in the interaction. This stage also explores how music can be used effectively to reminisce. If residents engage in positive interactions, their psychosocial needs can be met, leading to a reduction in BPSD.

#### Person-centred care

Person-centred care and personhood were two theories developed by Kitwood. Kitwood expressed the importance of an individual's psychological, social, and emotional needs, especially during dementia care. Person-centred care evolves around care being tailored and

Person-centred care- tailoring care to the needs of an individual. Consider preferences, needs and values to guide decisions and provide care that is respectful and responsive to the individual. Aim to include the individual in decisions as much as possible

Personhood- "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust."

designed around each individual's unique personality, preferences, wishes and strengths rather than focusing on their condition or impairments. Personcentred practises can allow residents to be perceived as more than their diagnosis and ensure that interactions and relationships are more meaningful. Person-centred care can allow residents to be more active in decision-making concerning their care and allows them to maintain their identity. Residents maintain the idea of self as an individual separate from their diagnosis, known as personhood, which Kitwood explored. Kitwood suggested fundamental psychological and social needs required by all humans to maintain good wellbeing and a sense of self. The six fundamental needs were: Love, Attachment, Identity, Comfort, Occupation, and Inclusion. Music can be used to ensure that residents psychological, social, and emotional needs are met and can be used by staff to recognise the resident as an individual.

Care staff can use music to connect with residents to ensure that all care is person-centred. At the same time, all music interactions should be person-centred to ensure that residents are receiving the most from the interaction. A PAMI Music Plan has been created to allow care staff to document resident's music

Music can ensure that the residents psychological, social and emotional needs are met

preferences to ensure that all music interactions are individualised and follow a person-centred philosophy. An example of a completed PAMI music plan has been included in the manual to assist with completing the plan for your residents.



#### **PAMI Music Plan**

The PAMI Music Plan template is provided separately from the manual to be able to make copies. Below presents an example of a resident's PAMI music plan.

• Name of resident

Emmeline Fischer

#### Special considerations for music choices

She was brought up in Germany moved to England when she was 23

English is her second language

Is a Christian and has a strong faith

What music activities would the resident want to participate in?

×	Singing	Choir	Dance	Music quiz
	Hymn	Concerts	music listeni	ng
×	Personal mus	ic listening	× <u>Other</u> (plea	se state what activity below)
	tergenerational lusic and moven			
• w	/hat music activ	ities have the re	sident previous	sly done
×	Sung in a choir	Gone to d	concert 🔉	Listened to the radio
×	Listened to a n	nusic collection	Played a r	nusical instrument
	Performed live	Other (ple	ease state what	activity below)
• G	enres the reside	nt is happy to li	sten to	
×	Pop Ro	ck 📃 Class	sical 🗙 Jazz	
	Opera 🗙 C	horal music 🗙	Hymns 🗙	Musicals
	Soul Otl	ner (please state	)	

<ul> <li>How does the resident want to listen to music?</li> </ul>	
🗙 CD Player 🛛 🗙 MP3/4 player 📃 Alexa/Google home	
Radio <u>Other(</u> please state)	
Either uses the communal CD player or Personal MP3 player	
<ul> <li>Is a music player available?</li> <li>X Yes</li> <li>No</li> <li>Sourcing one</li> </ul>	
<ul> <li>How does the resident like to listen to music? (add additional information on the type)</li> </ul>	pe)?
🗙 Headphones 🗧 Earphones 🗙 Portable speaker	
Fixed speaker Other (please state)	
She prefers over the head headphones that are wired with one lead.	
<ul> <li>Where does the resident like to listen to music?</li> <li>X Own living room</li> <li>X Communal living room</li> <li>Kitchen</li> </ul>	
🗙 Bathroom 🧧 Garden 🔀 Dining room	
Bedroom Other (please state)	
She likes to listen to personalised music in her own room but likes doing group music activi in the communal lounge	ities
<ul> <li>When in the day does the resident</li> <li>To wake up × Morning care</li> <li>Morning care</li> </ul>	
📒 As an activity 📒 Evening care 😕 <u>To</u> go to sleep 🗙 bathing	
Other (please state)	
<ul> <li>If used during care situations, what method of music does the resident prefer?</li> </ul>	
- In used during care situations, what method of music does the resident prefer:	
48	



× Recorded music <u>Other(please state</u>)

Joint singing for morning care

Recorded music for bathing and mealtimes

• What are the residents preferred volumes?

Low volume

• What are the residents favourite music

The Beatles

West end musicals- Sound of music, Dreamgirls, Mary Poppins

Frank Sinatra

 The preferred music choice for care tasks? These songs are to be <u>used as</u> cues

Morning care- Morning has broken

Bathing- Que Sera Sera

Lunch- Come fly with me

Meaningful music

Can't help falling in love with you Elvis Presley- Wedding song Abide with me, Jerusalem, Morning has broken (Important Religious songs)

 Music that creates a negative response War songs

# Danish documentary: The sound of life

- <u>https://www.tvmidtvest.dk/lyden-af-liv/lyden-af-liv-afsnit-</u> <u>1?autoplay=1#player</u>
- This video displays Jens one of the PAMI researchers from the Danish team.
- Jens is a music therapist who can be seen working with a group of resident in a care home in Denmark.
- The video is in Danish but you do not need to understand what is being said, instead watch Jens actions.
- What does he do to create a safe space?

# **Practical Skills- PAMI Music Plan**

A PAMI music plan has been create to assist with developing a personalised and tailored music plan for residents.

At the end of the training work with your resident to develop a personalised plan that can be used during care to ensure that all interactions and activities are person-centred.

The PAMI music plan has been provided separate so you are able to make copies However an example has been provided on page 46



# Appendix 5 Changes to Study Design Due to COVID-19

Element	Originally Study design	Covid adapted study design	Impact
Expert	Regular face-to-face expert	Questionnaires were distributed via care	Reduced amount of data collected. Staff
consultation	consultations to aid with the	home staff forums and research teams	were unable to be as involved in the
	development of the manual and	connections. Consulted with staff only	development due to the method and staff
	study	once.	being stressed due to COVID-19.
Recruitment	Nottingham ENRICH events,	Care homes involved in Lincolnshire In-	Relied on a third party to recruit and
	contacting local care homes. The	Reach Program. An In-Reach Practitioner	consent participants meaning the
	primary researcher to attend care	attended the care home to recruit and	researchers could not encourage a
	homes to recruit and consent	consent participants.	representative sample
	participants.		
Sample size	<u>Pilot study</u>	Manual field-testing	
	2 care homes	3 care homes	
	10 staff members	9 staff members	
	10 residents	9 residents	
	Feasibility study	Manual evaluation	
	4 care homes	5 care homes	

	24 staff members	25 staff members	
	24 residents	25 residents	
Training	In-person interactive training	Online interactive training containing	Unable to attempt the practical skills.
	containing opportunities to	activities that could be completed online	Harder to ensure staff attended.
	practice the skills		Unable to produce the videos due to the
	Videos presenting the skills		research team being unable to meet in
			person to film them.
Supervision	In-person supervision where staff	Online reflective sessions where staff	Unable to determine if staff were
	had the opportunity to attempt	shared experience and facilitators	implementing PAMI-UK or other music
	the interactions with residents	provided guidance	activities. Could only provide so much
	while the researchers watched to		guidance without knowing the resident.
	give feedback.		
	One staff member trained to be a		
	super-user to support other staff.		
Interview	In-person	Online	Less engagement from residents
	Staff and resident interview	Staff interviews and resident	
		questionnaires	

Qualitative	Diary entries (50% of staff	Diary entries	Some data collections not completed
data	complete)	Reflective prompt sheets	correctly
collection	25% of training sessions recorded	Reflective session transcripts	Unable to analysis specific interactions
	Recordings of interactions	Interviews	
	Interviews		
Quantitative	MMSE	DSRS	Outcome measures that did not require
data	SCIDS	SCIDS	the researchers were selected. There were
collection	MIDAS	MIDAS	issues with returning documents and
	Professional Care Team Burden	M-NCAS	missing data.
	(PCTB) scale		
	verbal and non-verbal interaction		
	scale		

# Appendix 6 REC Letter



#### London - Harrow Research Ethics Committee

Level 3, Block B Whitefriars Lewins Mead Bristol BS1 2NT

<u>Please note</u>: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

29 June 2021

Miss Bryony Waters Institue of Mental Health Jubilee Campus, University of Nottingham Innovation Park, Triumph Road, Nottingham NG7 2TU

Dear Miss Waters,

Study title:

REC reference: Protocol number: IRAS project ID: Development and evaluation of the Person Attuned Musical Interaction in dementia manual UK version (PAMI-UK) 21/LO/0283 21006 293613

Thank you for your letter of response on the  $22^{nd}$  of June 2021. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 18 June 2021

#### **Documents received**

The documents received were as follows:

Document	Version	Date	
Participant information sheet (PIS) [Staff Info Sheet Manual	3	18 June 2021	

Evaluation PAMI]		
Participant information sheet (PIS) [Resident Info Sheet Manual Evaluation PAMI]	3	22 June 2021
Research protocol or project proposal [Protocol Qualitative Study PAMI]	3	22 June 2021
Letters of invitation to participant [Manager Invitation Letter PAMI]	3	18 June 2021
Letters of invitation to participant [Staff Invite Letter PAMI]	2	18 June 2021
Other [Consultee Advice Form PAMI]	3	18 June 2021
Other [Consultee Info Sheet Manual Evaluation PAMI]	3	22 June 2021
Participant consent form [Staff Consent Form PAMI]	3	18 June 2021
Participant consent form [Resident Consent Form PAMI]	3	22 June 2021

# Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indementity]	1	16 March 2021
Interview schedules or topic guides for participants [Interview Guide Manual Development PAMI]	1	11 March 2021
Interview schedules or topic guides for participants [Interview Guide Manual Evaluation PAMI]	1	11 March 2021
IRAS Application Form [IRAS_Form_20052021]		20 May 2021
Letter from funder		27 September 2018
Letter from funder [Funding Email]	1	22 March 2021
Letter from sponsor [Sponsor Letter HRA REC]	3.0	11 March 2021
Letters of invitation to participant [Resident Invite Letter PAMI]	1	11 March 2021
Letters of invitation to participant [Manager Invitation Letter PAMI]	3	18 June 2021
Letters of invitation to participant [Staff Invite Letter PAMI]	2	18 June 2021
Non-validated questionnaire [Care Home Demographic Questionnaire PAMI]	1	11 March 2021
Non-validated questionnaire [Resident Demographic Questionnaire PAMI]	1	11 March 2021
Non-validated questionnaire [Staff Demographic Questionnaire PAMI]	1	11 March 2021
Non-validated questionnaire [Resident PAMI Experience PAMI]	1	11 March 2021
Non-validated questionnaire [Residents Demographic Q&A PAMI]	1	22 March 2021
Other [Delegation Log for LIP PAMI]	1	16 March 2021
Other [Sponsor Insurance letter 2020-21]	1	16 March 2021
Other [Consultee Letter PAMI]	1	22 March 2021
Other [Relative Letter PAMI]	1	22 March 2021
Other [Consultee Info Sheet Manual Development PAMI]	2	27 April 2021
Other [Manual Overview PAMI]	1	12 May 2021
Other [Consultee Advice Form PAMI]	3	18 June 2021

Other [Consultee Info Sheet Manual Evaluation PAMI]	3	22 June 2021
Participant consent form [Staff Consent Form PAMI]	3	18 June 2021
Participant consent form [Resident Consent Form PAMI]	3	22 June 2021
Participant information sheet (PIS) [Staff Info Sheet Manual Development PAMI]	2	27 April 2021
Participant information sheet (PIS) [Resident Info Sheet Manual Development PAMI]	2	27 April 2021
Participant information sheet (PIS) [Simplistic Info Sheet Manual Development PAMI]	2	28 April 2021
Participant information sheet (PIS) [Simplistic Info Sheet Manual Evaluation PAMI]	2	28 April 2021
Participant information sheet (PIS) [Staff Info Sheet Manual Evaluation PAMI]	3	18 June 2021
Participant information sheet (PIS) [Resident Info Sheet Manual Evaluation PAMI]	3	22 June 2021
Research protocol or project proposal [Protocol Qualitative Study PAMI]	3	22 June 2021
Sample diary card/patient card [Diary Entry Manual development PAMI]	1	11 March 2021
Sample diary card/patient card [Diary Entry Manual Evaluation PAMI]	1	11 March 2021
Summary CV for Chief Investigator (CI) [PI McDermott CV 2021]	1	11 March 2021
Summary CV for student [Academic CV Bryony ]	1	11 March 2021
Summary CV for supervisor (student research) [Supervisor CV]	1	22 March 2021
Validated questionnaire [QUALIDEM Outcome measure ]	1	22 March 2021
Validated questionnaire [MiDAS music engagement Outcome measure]	1	22 March 2021
Validated questionnaire [SCID Staff competence Outcome Measure]	1	22 March 2021
Validated questionnaire [Dementia Severity Rating Scale Outcome Measure]	1	22 March 2021
Validated questionnaire [M-NCAS Staff Burden outcome Measure]	1	22 March 2021

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

IRAS Project ID: 293613

Please quote this number on all correspondence

Yours sincerely

A to

Christopher Cole HRA Approvals Officer

E-mail: harrow.rec@hra.nhs.uk

# Appendix 7 HRA Approval Letter

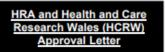


Dr Orii McDermott Institute of Mental Health Jubilee Campus, University of Nottingham Innovation Park, Triumph Road, Nottingham NG7 2TU NHS Health Research Authority

Email: approvals@hra.nhs.uk HCRW.approvals@wales.nhs.uk

29 June 2021

Dear Dr McDermott



Study title:	Development and evaluation of the Person Attuned Musical Interaction in dementia manual UK version (PAMI-UK)
IRAS project ID:	293613
Protocol number:	21006
REC reference:	21/LO/0283
Sponsor	University of Nottingham

I am pleased to confirm that <u>HRA and Health and Care Research Wales (HCRW) Approval</u> has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

# How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland. How should I work with participating non-NHS organisations? HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures. What are my notification responsibilities during the study? The standard conditions document "After Ethical Review - guidance for sponsors and investigators", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including: Registration of research Notifying amendments Notifying the end of the study The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures. Who should I contact for further information? Please do not hesitate to contact me for assistance with this application. My contact details are below. Your IRAS project ID is 293613. Please quote this on all correspondence. Yours sincerely, Carolyn Halliwell Approvals Specialist Email: approvals@hra.nhs.uk Ms Angela Shone Copy to:

# List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indementity 2020-21]	1	16 March 2021
Manual Development PAMI V1.0 11.03.21]	1	11 March 2021
Interview schedules or topic guides for participants [Interview Guide Manual Evaluation PAMI V1.0 11.03.21]	1	11 March 2021
IRAS Application Form [IRAS_Form_20052021]		20 May 2021
Letter from funder		27 September 2018
Letter from funder [Funding Email]	1	22 March 2021
Letter from sponsor [Sponsor Letter HRA REC V3.0]	3.0	11 March 2021
Letters of invitation to participant [Manager Invitation Letter PAMI V2.0 29.04.21]	3	18 June 2021
Letters of invitation to participant [Staff Invite Letter PAMI V1.0 11.05.21]	2	18 June 2021
Letters of invitation to participant [Resident Invite Letter PAMI V1.0 11.05.2021]	1	11 March 2021
Non-validated questionnaire [Care Home Demographic Questionnaire PAMI V1.0 11.03.21]	1	11 March 2021
Non-validated questionnaire [Resident Demographic Questionnaire PAMI V1.0 11.03.21]	1	11 March 2021
Non-validated questionnaire [Staff Demographic Questionnaire PAMI V1.0 11.03.21]	1	11 March 2021
Non-validated questionnaire [Resident PAMI Experience PAMI V1.0 11.03.21]	1	11 March 2021
Non-validated questionnaire [Residents Demographic Q&A PAMI V1.0 11.03.21]	1	22 March 2021
Organisation Information Document		
Other [Consultee Letter PAMI V1.0 11.03.21]	1	22 March 2021
Other [Relative Letter PAMI V1.0 11.03.21]	1	22 March 2021
Other [Delegation Log for LIP PAMI v1.0 11.03.21]	1	16 March 2021
Other [Sponsor Insurance letter 2020-21]	1	16 March 2021
Other [Consultee Info Sheet Manual Development PAMI V2.0 27.0421]	2	27 April 2021
Other [Manual Overview PAMI V1.0 12.05.2021]	1	12 May 2021
Other [Consultee Advice Form PAMI V2.0 29.04.21]	3	18 June 2021
Other [Consultee Info Sheet Manual Evaluation PAMI V2.0 27.04.21]	3	22 June 2021
Participant consent form [Staff Consent Form PAMI V2.0 29.04.21]	3	18 June 2021
Participant consent form [Resident Consent Form PAMI]	3.0	22 June 2021
Participant information sheet (PIS) [Staff Info Sheet Manual Evaluation PAMI V2.0 27.0421]	3	18 June 2021
Participant information sheet (PIS) [Resident Info Sheet Manual EvaluationPAMI V2.0 27.04.21]	3	22 June 2021
Participant information sheet (PIS) [Staff Info Sheet Manual Development PAMI V2.0 27.04.21]	2	27 April 2021
Participant information sheet (PIS) [Resident Info Sheet Manual Development PAMI V2.0 27.0421]	2	27 April 2021
Participant information sheet (PIS) [Simplistic Info Sheet Manual	2	28 April 2021

Development PAMI V2.0 28.04.21]		
Participant information sheet (PIS) [Simplistic Info Sheet Manual Evaluation PAMI V2.0 28.04.21]	2	28 April 2021
Research protocol or project proposal [Protocol Qualitative Study PAMI V2.0 05.05.21]	3	22 June 2021
Response to Request for Further Information [Response to Queries]		
Response to Request for Further Information [Response to PO Points]		
Sample diary card/patient card [Diary Entry Manual development PAMI V1.0 11.03.21]	1	11 March 2021
Sample diary card/patient card [Diary Entry Manual Evaluation PAMI V1.0 11.03.21]	1	11 March 2021
Schedule of Events or SoECAT [IRAS schedule Events PAMI V1.0 11.03.21]	1	11 March 2021
Schedule of Events or SoECAT [SoECAT tool PAMI Developmental study]	1	19 May 2021
Schedule of Events or SoECAT [SoECAT tool PAMI Evaluation study]	1	19 May 2021
Summary CV for Chief Investigator (CI) [PI McDermott CV 2021]	1	11 March 2021
Summary CV for student [Academic CV Bryony ]	1	11 March 2021
Summary CV for supervisor (student research) [Supervisor CV]	1	22 March 2021
Validated questionnaire [QUALIDEM Outcome measure ]	1	22 March 2021
Validated questionnaire [MiDAS music engagement Outcome measure]	1	22 March 2021
Validated questionnaire [SCID Staff competence Outcome Measure]	1	22 March 2021
Validated questionnaire [Dementia Severity Rating Scale Outcome Measure]	1	22 March 2021
Validated questionnaire [M-NCAS Staff Burden outcome Measure]	1	22 March 2021



#### London - Harrow Research Ethics Committee

Level 3, Block B Whitefriars Lewins Mead Bristol BS1 2NT

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

22 March 2022

Miss Bryony Waters Institue of Mental Helath Jubilee Campus, University of Nottingham Innovation Park, Triumph Road, Nottingham NG7 2TU

Dear Miss Waters

#### Study title:

REC reference: Protocol number: Amendment number: Amendment date: IRAS project ID: Development and evaluation of the Person Attuned Musical Interaction in dementia manual UK version (PAMI-UK) 21/LO/0283 21006 SA01 21006 28 February 2022 293613

The above amendment was reviewed by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Completed Amendment Tool [Completed Amendment tool]	2	
Other [Consultee Advice Form PAMI]	4	15 March 2022
Other [Staff Info Sheet Manual Evaluation]	5	15 March 2022
Other [Resident Info Sheet Manual Evaluation PAMI]	5	15 March 2022
Other [Consultee Info Sheet Manual Evaluation]	5	15 March 2022

A Research Ethics Committee established by the Health Research Authority

Other [PAMI study summary]	2	15 March 2022
Participant consent form [Staff Consent Form PAMI]	4	15 March 2022
Participant consent form [Resident Consent Form PAMI]	4	15 March 2022
Research protocol or project proposal [Protocol Qualitative Study PAMI]	5	15 March 2022

#### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

#### Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

#### Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities— see details at: <u>https://www.hra.nhs.uk/planning-and-</u> improving-research/learning/

IRAS Project ID - 293613:

Please quote this number on all correspondence

Yours sincerely

Dr Megan Davies Chair

E-mail: harrow.rec@hra.nhs.uk

Enclosures:

List of names and professions of members who took part in the review

A Research Ethics Committee established by the Health Research Authority

#### London - Harrow Research Ethics Committee

# Attendance at Sub-Committee of the REC meeting on 11 March 2022 via correspondence

#### **Committee Members:**

Name	Profession	Present	Notes
Ms Elizabeth Chuck	Research Integrity Officer	Yes	
	Head of MRC Centre, Cambridge (retired)	Yes	

#### Also in attendance:

Name	Position (or reason for attending)
Mr Jacob Pinfield	Approvals Administrator

A Research Ethics Committee established by the Health Research Authority

# Appendix 9 Staff Participant Information Sheets



Participant Information Sheet (Final version 3.0: 18.06.2021)

# IRAS Project ID: 293613

Title of Study: Development and evaluation of the Person Attuned Musical Interaction in Dementia Manual UK version (PAMI-UK)

Name of Chief Investigator: Dr Orii McDermott Local Researcher(s): Bryony Waters & Martin Orrell (Information in red needs changing depending on if used for the manual development study or manual evaluation study)

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

# What is the purpose of the study?

In recent years there has been an increase in research on the benefits of music within dementia care. This has ranged from formal interventions provided by music therapists to individuals listening to music. Within care homes, reports suggest that residents can experience insufficient interaction, with many residents having direct contact with others for as little as 10% of the day. Lack of interaction could be due to residents with dementia inability to communicate. Formal music therapy sessions have highlighted that music can help residents with dementia develop meaningful interactions, feel less anxious, agitated and depressed, and communicate in an alternative way to verbal communication. However, formal music therapists are not available to all care homes due to funds and therapist availability. Music therapist currently provide some therapeutic music skills to staff and families through skill-sharing. There is evidence that many care home staff already use these therapeutic skills without realising. But currently, there is no formal manual to provide staff with the knowledge and support to use therapeutic music skills within daily routine and music activities. The Person Attuned Musical Interaction in dementia manual (PAMI) aims to be a structured staff training tool to incorporate musical skills and music into care homes. This study is the manual's initial testing, which will provide results on how the manual works in care homes and the feedback you provide on using the manual will aid revisions to improve the Manual 's appropriateness and usability in care homes.

# Why have I been invited?

You are being invited to participate because you are a member of care staff at a care home in the East Midlands or Lincolnshire that cares for people living with dementia. Participating care homes were selected through the organisation ENRICH (Enabling Research in Care Homes) or letters to your care home manager. We are inviting (9/25) participants like you to participate, (3/5) of which are from the same care home.

# Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part in the study, a video call or in-person meeting will be organised with a member of the research team to go through the study documents, double-check that you are eligible to participate, and provide you with an opportunity to ask any questions. If you still wish to participate in the study, you will be asked to sign a consent form that is provided and to return the consent form to the research team either in person, electronically or via a pre-paid envelope provided. The research team will then sign the consent form and return a copy of the consent form for you to keep. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

# What will happen to me if I take part?

From the start of the study to completion, the study will take (2 1/2) (4 1/2) months. All aspects of the study will take place in the care home you work at, at a time that is convenient for staff and management.

On day one, each staff member will be paired with a participating resident; we aim to pair staff members with the resident they work the most with. Once both residents and staff have been recruited, we will work with you to decide on the most appropriate participating resident to pair you with throughout the study. The resident you are paired with will be the individual you will use the PAMI skills with. (At the beginning of the study you will be asked to complete a series of questionnaires. Some will relate to yourself and your experience working in the care homes. The others will ask questions about your paired resident. You will be required to complete the questionnaires again at the end of the study. It will take approximately 20 minutes to complete)

Data collected from the questionnaires

- Music in Dementia Assessment care staff scale (MIDAS)- Residents music engagement
- QUALIDEM- Resident quality of life
- Sense of Competence in Dementia Care Staff Scale (SCIDS)- Staff confidence in dementia care

# Modified Nursing Care Assessment (M-NCAS)- staff stress and pressures

You will be asked to complete a demographic questionnaire about yourself, including questions on your age, gender, and time at the care home. The completing of the demographic question will take a few minutes. Residents will be asked to complete a demographic questionnaire and may need your assistance to complete it. The amount of input required will depend on the resident's impairments and abilities. The questions include age, gender and how long they have lived at the care home. A nominated staff member will also be asked to complete the care home demographic questionnaire. The time it takes to assist with the resident's demographic questionnaire will be dependent on the resident needs. On day one, you will also be asked to complete the care home to collect data on the resident participants dementia. Completion of the dementia severity scale takes approximately 10-15 minutes.

# Training

(Staff will be asked to provide an individualised email address, this email will be used to provided the training, reflective session and interview. You will be sent a reminder the day before. The email will not be used to collect any study related information or for you to return documents to the research team) Once the demographic questionnaires have been completed, you will be invited to attend a workshop to learn more about the PAMI manual and how you can use it within your care home. The training session will last approximately 3 hours and will be organised around the availability and convivence of your schedule and the care home. Currently, due to Covid, all training will be online via the software Microsoft teams. The training will ideally take place in a quiet location of the care home, where you have access to both the internet and a computer to complete the training. You will complete the training with other participating staff members at your care home, as some of the activities during the training requires teamwork. During the training, you will also be required to have the manual at hand to work through. Additional information will be provided to both yourself and the care home on how to use teams if you are unfamiliar with the software. Videos of the PAMI skills incorporated into practice will be available for you to return to throughout the study to reinforce what has learnt. The Training session consists of theory and practical elements that provided you with the PAMI skills and how you can use them.

# <u>PAMI</u>

PAMI is a care staff training tool for members of staff who have direct daily interactions with individuals with dementia to provide them with musical skills and activities that are generally reserved for music therapy. PAMI aims to improve staff-resident interactions by providing the skills for both staff and residents to have more meaningful interactions that ensure that residents psychological, social and emotional needs are met. PAMI also

highlights the use of music and non-verbal communication for residents to communicate and express themselves when verbal language may be impaired. The tool consists of a paper manual and interactive webinar.

The manual begins by discussing PAMI's theory, including communication style and research on the benefits of music in care homes. The manual then progresses onto the voice; in this section, you will learn to become more aware of your voice and the musical elements of the voice that can be changed in relation to your resident's behaviour and mood. You will also have time to explore your voice to become comfortable with using it more within your work. The manual will then move on to Framing; this section provides skills on music to cue to specific times, events, tasks and people. Framing also explores the sound environment of care homes and how different sounds can be added or removed to improve the environment for residents. The section on regulation explores how music and musical elements can be altered and adapted in relation to the resident's arousal and emotional state to either get residents out of states of apathy or reduce resident's agitation. You will also learn skills to recognise your emotional states during care home situations to reduce staff stress. The Final set of skills are under relation where you will learn about PAMI music plans that allows staff to develop a personalised plan of resident's music preferences. In relation, you will also discover how music that is special to individuals can be used to create conversation and allow individuals to reminisce about their life history. The final section of the manual will provide you with practical hints and tips for using music in care. This section will also provide you with a list of suggested songs to help provide you with a starting point of songs to include in your practice.

PAMI has been developed based on person-centred approaches. How PAMI is incorporated into routines will be dependent on the care home, the care staff and the needs and preferences of the resident with dementia. Similarly, the type of music activities and songs used should be based on the resident preferences. The PAMI music plan should be tailored to individuals and be created by working with the resident and their relatives. The PAMI activities are not ridged or structured at a specific time or duration. Care staff should use the skills in their routine and tasks when they think is most appropriate and beneficial for the residents. Understanding when to use skills will be explored during the training.

# Using PAMI and reflective sessions

Care staff will then be expected to use the PAMI manual with residents for (8/18) weeks. The use of the PAMI manual will be integrated into your daily care routine; therefore, we expect that the use of PAMI should not require additional time. There is no set time or frequency for using the PAMI skills. When you use the skills and how often you use the skills will be determined by yourself. These decisions should be based on when you believe your resident will benefit most from including music and musical skills into their routine. However, we do expect you to use the skills on every shift and regularly throughout the shift. You will be required to document your experience of PAMI. Each staff member will receive a diary entry template to complete; this should be used to document when the skills were used, the skills used and how the resident reacted during the interaction. The research team ask that you document every time you use the skills, but these can be complete all in one go at the end of your shift if this is easier. Filling out the diary entry will only take a few minutes and can be used by yourself to monitor which skills are most appropriate and effective for the resident.

You will be required to attend fortnightly reflective sessions; over the course of the study, you will attend a total of (3/8) sessions which will last a maximum of 30 minutes. These sessions will be group sessions with other members of your care home. However, if care staffs schedules do not allow for group sessions, 1:1 session can also be offered. The sessions are an opportunity for you to reflect on how you have currently incorporated the PAMI skills into your routine and how you could use the skills you learnt further. The sessions are a time for you to receive support from the researchers on any area of PAMI you may be struggling with. Throughout the sessions, you will be provided with a number of prompt activities to help you reflect. (The MIDAS and reflective prompt sheets are completed during the reflective sessions)

(At the end of the 18 weeks, you will be asked to complete the SCIDS, QUALIDEM and M-NCAS again. It will take approximately 20 minutes to compete the set of questionnaires.) (At the end of the study,) residents will be asked to complete a post-intervention questionnaire about their experience with PAMI; if the researchers are unable to attend the care home due to Covid, you may be required to assist them with completing the questionnaire. The questionnaire should be completed within the first week after finishing using the PAMI skills. The time taken to complete the questionnaire will be dependent on the resident's impairments.

# <u>Interview</u>

After the (8/18) weeks, interviews will be held, which will give you an opportunity to provide feedback on your experience with PAMI and any adjustments you feel need to be made to the manual. Interviews are expected to last between 30 mins to 1 hour. The interviews will be scheduled for a convenient time for participants and the care homes, but the research team will aim to schedule them for the first week after the end of using PAMI. Due to current circumstances with COVID, interviews may take place online using teams. If the situation does change, the interviews will take place in the care home. As long as you are happy, the interviews will be audio recorded. If you do not wish for the interviews to be audio recorded, the interviewer will ask if it is okay to take notes. Recordings will be stored on a password-protected computer in a secure room at the University of Nottingham. As soon as recordings have been transferred to the computer, they will be erased from the recording device. The recordings will only be available to authorised members of the research team. The recording of the interview will then be transcribed. At this stage, any identifiable information will be removed.

#### Expenses and payments

Participants will not be paid an inconvenience allowance to participate in the study

#### What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risk of taking part in this study. We have aimed to develop a tool that limits the amount of additional pressures, stress and burden placed on care staff. PAMI will be integrated into your current daily routine and therefore should not be an inconvenience for you or add significant burden, stress, or pressure to your current role. We hope that the skills learnt may make completing tasks more efficient and therefore may reduce current stress and burden. There may be some additional burden as a result of the training and data collection. The researchers have tried to keep this to a minimum by limiting the length of training. We are also only collected vital data to limit the burden on completing questionnaires and documentation. Care staff will be required to complete one 3 hour training session, (3/8) half-hour reflective sessions and one half-hour interview over the (10/20) weeks; this could add some burden for staff. However, we will arrange all sessions around the convenience and availability of you and the care home. The documentation of the skills used will take a few minutes, and although they need to be recorded daily, it can be completed at a convenient time. (The data collected from the questionnaires will take approximately 20 minutes).

We do not expect that PAMI will cause any disadvantage or risk to the residents you work with. However, if any residents display distress while using PAMI, stop using the manual with them immediately. It is possible that the songs you use with the residents may cause upset due to evoking emotional memories. If you feel that the song is causing the resident distress, stop using the song and document it in their PAMI music care plan. During the reflective sessions, the researchers will ask you to report any issues that have arisen with using the manual with residents.

All the results, views, and opinions you provide in the study will be anonymised, and confidential personal information will not be disclosed to anyone outside of the research team. Your employment at the care home will not be affected by taking part in or by withdrawing from the study.

#### What are the possible benefits of taking part?

We cannot promise the study will help you, ( but the information we collect will further develop the manual and make adjustments to complete future studies) (but the information we get from this study may help to provide music therapeutic skills to care homes) We hope that the PAMI manual may improve resident-staff interactions, which could improve dementia symptoms and quality of life. Research into music interventions has suggested that music interventions improve residents' outcomes and impact staff positively by reducing staff burden and increasing job satisfaction.

# What happens when the research study stops?

At the end of the study, the data we have collected will be analysed and used to produce part of Bryony Waters PhD thesis. The information that we have collected will also be used to adapt the manual and make adjustments for future studies. Data collected may also be used for publication or conferences. All participating care homes will receive a summary of the results found from the study.

# What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can contact Louise Sabir, contact for the Faculty of Medicine and Health Sciences ethics committee, University of Nottingham (ResearchEthics@nottingham.ac.uk). The complaint process will depend on each care home policies. This will be discussed with the manager, and information will be provided at the beginning of the study.

In the event that something does go wrong, and you are harmed during the research, and this is due to someone's negligence, then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

# Will my taking part in the study be kept confidential?

We will follow ethical and legal practice, and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database at the University of Nottingham. Under UK Data Protection Laws, the University is the Data Controller (legally responsible for the data security), and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant, and we will do our best to meet this duty. Information about you that leaves the care home will have your name and address removed, and a unique code will be used so that you cannot be recognised from it.

Your contact information will be kept by the University of Nottingham for 1 year after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time, your data will be disposed of securely. During this time, all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's, and our funders' policies, we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified), but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything or the research team observe a situation that we feel puts you or anyone else at any risk or if your health and/or rights are being infringed, we may feel it necessary to report this to the appropriate persons. Therefore, confidentiality will be broken to disclose this to the relevant authority. Participants will be informed if confidentiality has to be broken for this reason.

All identifiable information will be removed from the results prior to analysis and write up. All results will be anonymous, with participants being given pseudo names to protect their identity.

# What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records, and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

# What will happen to the results of the research study?

After completion of the study, results will be used towards Bryony Waters PhD thesis. Results may also be presented at dementia conferences or to produce a publishable journal article. The data will also be used to make alterations to the PAMI manual.

# Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by The Music Therapy Charity.

# Who has reviewed the study?

All research in healthcare is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The London-Harrow Research Ethics Committee.

# Further information and contact details

Chief Investigator- Dr Orii McDermott Position- Senior Research Fellow Email- <u>orii.mcdermott@nottingham.ac.uk</u> Address- Division of Psychiatry and Applied Psychology Institute of Mental Health University of Nottingham Jubilee Campus Nottingham NG8 1BB, UK

Researcher- Bryony Waters Position- PhD student Email- bryony.waters@nottingham.ac.uk Address- Division of Psychiatry and Applied Psychology Institute of Mental Health University of Nottingham Jubilee Campus Nottingham NG8 1BB, UK Thank you for reading this

# Appendix 10 Resident Information Sheet



# Resident Participant Information Sheet (Final version 2.0: 27.04.2021) (Information in red needs adapting depending on manual development study or manual evaluation study)

# IRAS Project ID: 293613

**Title of Study**: Development and evaluation of the Person Attuned Musical Interaction in Dementia Manual UK version (PAMI-UK)

Name of Chief Investigator: Dr Orii McDermott Local Researcher(s): Bryony Waters & Martin Orrell

We would like to invite you to take part in our research study. Before you decide, we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. A staff member of the care home will also be able to go through the sheet with you. Talk to others about the study if you wish. Ask us if there is anything that is not clear. If you have any questions, inform a staff member, and they will pass any questions on to the researchers. Alternatively, there are question and concern forms available for you to fill and with pre-paid envelopes to send questions straight to the research team.

# What is the purpose of the study?

In recent years there has been an increase in research on the benefits of music within dementia care. This has ranged from formal interventions provided by music therapists to individuals listening to music. Care homes reports suggest that residents can experience insufficient interaction, with many residents having direct contact with others for as little as 10% of the day. Music research has highlighted music can help residents with dementia develop meaningful interactions, feel less anxious, agitated and depressed and communicate in an alternative way to verbal communication. There are a number of music activities and skills that care staff can use during their daily routine, and many staff already use these skills. However, currently, there is no structured training manual to guide and support staff in using these skills with residents. The Person Attuned Musical Interactions (PAMI) manual aims to provide care staff with music skills that can be integrated into routines. The study will test the manual to see if it is suitable to be used with resident and staff in care homes.

#### Why have I been invited?

You are being invited to take part because you are a resident with a diagnosis of dementia at a participating care home in the East Midlands. Participating care homes were selected through the organisation ENRICH (enabling research in care homes) or letters to the care home. We are inviting (9/25) participants like you to participate, (3/5) of which are from the same care home.

#### Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you do decide to take part in the study, a video-call or in-person meeting will be organised with a member of the research team to go through the study documents, double-check that you are eligible to take part, check that you are able to consent and provide you with an opportunity to ask any questions. If you still wish to participate in the study and are deemed able to consent, you will be asked to sign a consent form that is provided and to return the consent form to the research team either in person, electronically or via a pre-paid envelope provided. The research team will then sign the consent form and return a copy of the consent form for you to keep. Care staff or a relative can assist you with organising the meeting. If you are deemed unable to consent, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights or care provided.

#### What will happen to me if I take part?

From the start of the study to completion, the study will take (2 ½) (4 ½) months. Staff members at your care home will attend training to learn how to use the PAMI manual within the care home. They will then use the music skills and activities with you and your fellow residents to improve interactions between residents and care staff for the next eight weeks. During this time, you are not required to do anything different from your usual day, other than engage with staff using the manual if you wish to. You will be paired with a staff member; this will be a member of staff you have close contact with regularly. You will be asked to complete a demographic questionnaire, including questions about your age, gender and time at the care home. It should only take a few minutes to complete the questionnaire, but the time required may vary between individuals and you should not feel rushed or pressured to complete it in a specific amount of time. A staff member or relative can assist you with completing the questionnaire. Staff will be asked to complete the dementia severity scale to provide the research team with data on your dementia. (At the beginning and end of the study, your paired staff member will complete some questionnaires about your experience at the care home) Data collected from the questionnaire include:

#### Music In Dementia Assessment Scale (MIDAS)- music engagement

#### QUALIDEM- Quality of Life

At the end of the study, you will be asked to complete a questionnaire about your experience with PAMI. . Questions will include your enjoyment of the activities and how interactions have changed. If researchers are able to attend the care home, the questionnaire will be completed with the researcher. However, if this is not the case, you can have assistance from a staff member or relative. If there is sensitive information you wish to include that you do not want staff members to read, alternative arrangements can be made to assist you with completing the questionnaire. It should approximately 10 minutes to complete the questionnaire, but the time required may vary between individuals and you should not feel rushed or pressured to complete it in a specific amount of time.

If you have any concerns, questions or issues, you can speak to the researcher in person if they are able to attend the care home under covid guidelines. Otherwise, you can ask the staff member or manager to contact the researchers. If you would like to discuss something sensitive and do not want the care staff to know, confidential concern forms will be available for you to write any questions, concerns, or issues on. The forms will be accompanied by a pre-paid envelope which can be sent directly to the researchers. Alternatively, you can ask a relative to contact the researchers; a letter has been sent to them with the researchers' contact details.

# What is PAMI?

PAMI is a care staff training tool for members of staff who have direct daily interactions with you to provide them with musical skills and activities that are generally reserved for music therapy. PAMI aims to improve staff-resident interactions by providing the skills for both staff and residents to have more meaningful interactions that ensure that residents needs are met. PAMI also highlights how you can use music and non-verbal communication to communicate and express yourself when verbal language may be challenging.

During the staff, training staff will learn the theory behind PAMI, including communication style and the benefits of music in care homes. The manual will then explore how staff can use their voice and how it can be adapted and altered in relation to residents needs and moods. The next section will explore how music can help residents recognise a specific time, event or task. Staff will also learn how sounds can be added or removed from the care home to make the environment more pleasant for residents. Staff will also learn how different music can be used when you are in different moods to help you work through emotions. The final part of the training will teach staff how to use music that is important to you to start conversations with you and help you remember and discuss memories relating to the songs.

PAMI has been developed based on person-centred approaches. How the PAMI skills are used will depend on the care home, the care staff, and your needs and preferences. Similarly, the type of music activities and songs used should be based on your preferences staff will work with you and your relatives to tailor the music activities and skills to what you want. The PAMI activities are not ridged or structured at a specific time or duration. You and the care staff should use the skills in routines and tasks when both of you think it is most appropriate and beneficial for you.

### **Expenses and payments**

Participants will not be paid an inconvenience allowance to participate in the study

### What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages or risk of taking part in this study. PAMI has been developed to make interactions and care home routines smoother and efficient. Therefore, we hope that using PAMI will not increase stress or burden or inconvenience for you. PAMI will be integrated into your current daily routine and, therefore, should not be an inconvenience for you. We hope the use of PAMI will not add any additional time to your current tasks and should not be any additional burden for you. When care staff use the PAMI skills, you do not have to do anything that you do not want to, including engaging with the activities. If there is anything during the study that you do not like, you can inform the staff member or researchers, and that task or activity will be stopped immediately. You will be asked to complete two questionnaires, one at the beginning and one at the end, it should only take a few minutes to complete each, but this will be dependent on each individual. If you need any help to complete the questionnaire, you can ask the care staff, a relative, or the researcher (if they are attending the care home). You may be asked some sensitive questions such as communication style and interactions with staff. Participants do not have to answer any questions that are sensitive if they do not wish to. The care home and staff members will not know your answers unless you ask staff to help with completing the questionnaire. If you require assistance with the questionnaire containing sensitive information that you do not want staff to see, either a relative can assist or other arrangements can be made.

Your participation in the study and any answers provided will not affect the care you receive.

If you display distress while using PAMI or find some of the songs upsetting, inform a staff member, and they will stop using the techniques immediately.

# What are the possible benefits of taking part?

We cannot promise the study will help you, but the information we get from this study will be used to develop the manual further and make changes to complete future studies of the manual. We hope that the PAMI manual may improve resident-staff interactions, which could improve dementia symptoms and quality of life.

### What happens when the research study stops?

At the end of the study, the data we have collected will be analysed and used to produce Bryony Waters PhD thesis. (The information that we have collected will also be used to adapt the manual and make changes for future studies of the manual.) Data collected may also be used for publication or conferences.

#### What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Alternatively, speak to a member of staff who can contact the researcher with your concerns. The researchers' contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Patient Advice and Liaison Service, if you live in an NHS care home, who offer confidential advice, support and information on health-related matters for patients and their family. You can find your nearest PALS office on the NHS website (https://www.nhs.uk/) or ask your GP surgery or hospital. If you are not an NHS resident, if you remain unhappy and wish to complain formally, you can contact Louise Sabir, contact for the Faculty of Medicine and Health Sciences ethics committee, University of Nottingham (ResearchEthics@nottingham.ac.uk). The complaint process will depend on each care home policies. This will be discussed with the manager, and information will be provided at the beginning of the study.

In the event that something does go wrong and you are harmed during the research, and this is due to someone's negligence, then you may have grounds for a legal action for compensation against the University of Nottingham, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

#### Will my taking part in the study be kept confidential?

We will follow ethical and legal practice, and all information about you will be handled in confidence.

If you join the study, we will use information collected from you during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database at the University of Nottingham. Under UK Data Protection Laws, the University is the Data Controller (legally responsible for the data security), and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights, we will use the minimum personally–identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant, and we will do our best to meet this duty.

Information about you which leaves the care home will have your name and address removed, and a unique code will be used so that you cannot be recognised from it.

Your contact information will be kept by the University of Nottingham for 1 year after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected, and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time, all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies, we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified), but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything or the research team observe a situation that we feel puts you or anyone else at any risk or if your health and/or rights are being infringed, we may feel it necessary to report this to the appropriate persons. Therefore, confidentiality will be broken to disclose this to the relevant authority. Participants will be informed if confidentiality has to be broken for this reason

All identifiable information will be removed from the results prior to analysis and write up. All results will be anonymous, with participants being given pseudo names to protect their identity.

#### What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights or care being affected. If you withdraw, we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records, and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

### What will happen to the results of the research study?

After completion of the study, results will be used towards Bryony Waters PhD thesis. Results may also be presented at dementia conferences. The data will also be used to make changes to the PAMI manual.

#### Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by The Music Therapy Charity.

#### Who has reviewed the study?

All research in healthcare is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by London-Harrow Research Ethics Committee.

#### Further information and contact details

Chief Investigator- Dr Orii McDermott Position- Senior Research Fellow

# Email- Orii.mcdermott@nottingham.ac.uk

Address- Division of Psychiatry and Applied Psychology Institute of Mental Health University of Nottingham Jubilee Campus Nottingham NG8 1BB, UK

Researcher- Bryony Waters Position- PhD student Email- bryony.waters@nottingham.ac.uk Address- Division of Psychiatry and Applied Psychology Institute of Mental Health University of Nottingham Jubilee Campus Nottingham NG8 1BB, UK

# Thank you for reading this

# Appendix 11 Dementia-friendly Resident Information Sheet



Participant Information Sheet (manual development study residents) (Final version 2.0:28.04.2021)

IRAS Project ID: 293613

**Title of Study:** Development and evaluation of the Person Attuned Musical Interaction in Dementia Manual UK version (PAMI-UK)

Name of Chief Investigator: Dr Orii McDermott Local Researcher(s): Bryony Waters & Martin Orrell

I am Bryony Waters, a researcher at the University of Nottingham, who is part of the PAMI study. My picture is on the right.



We would like to invite you to take part in our research study. A staff member will go through the information sheet with you, and we can answer any questions you have.

 Research into the music for people living with dementia, especially in long-term care, has shown benefits, including improving staff-resident communication.

MY PROJECT

- My project is about developing a manual (PAMI) that can provide care staff with musical techniques to be used with residents like yourself to improve communication.
- We aim to test the manual in care homes and gain feedback on how it works in care homes.
- You are being invited to take part because you are a resident at this care home with a diagnosis of dementia. We are inviting (9/25) participants like yourself to participate, (3/5) of which are from the same home.

# THE STUDY AND YOUR INVOLVEMENT

• The study will run for (2/4) months. You will be paired with a member of staff to participate with.

• The staff member will use the skills they have learnt by including them in daily tasks. During this time, they will write down when they use the skills with you and their thoughts.

 During this time, you are not required to do anything different from your usual day, to engage with staff and the activities if you wish.

- At the beginning of the study, you will be asked to provide some information about yourself. You can ask for assistance to complete this from a staff member or relative.
- At the end of the study, you will be asked to provide some information on your experience with PAMI. This may be with one of the researchers, staff member or relative.

# BENEFITS AND RISKS

- We do not expect any risk or harm to you taking part in the study. If you display any distress, inform a staff member, and they will stop using the skills immediately.
- We cannot promise the study will help you, but the information we collect we hope may help to improve resident-staff interaction and quality of life. We also hope that you will enjoy the music activities.

# PARTICIPATION

- Your participation is voluntary, and you do not need to partake in the study if you do not wish to.
- You can withdraw from the study at any time without giving a reason. If you withdraw, your legal rights or care will not be affected. If you withdraw, we will no longer collect any

information about you, but we will keep the information we have already collected.

If you have any concerns, you can speak to a member of staff who can speak to the researcher.

All information collected from you during the study will be kept strictly confidential.

# Appendix 12 Participant Information Sheet - Consultee

Participant Information Sheet - CONSULTEE

(Final version 2.0:27.04.2021)

IRAS Project ID: 293613

Title of Study: Development and evaluation of the Person Attuned Musical Interaction in Dementia Manual UK version (PAMI-UK)

Name of Chief Investigator: Dr Orii McDermott

Local Researcher(s): Bryony Waters & Martin Orrell

# Invitation

Your relative (it could also be a friend or someone you care for, but for brevity, this document will use the term 'relative') is being invited to take part in a research study. Before you decide whether you agree to their participation, it is important for you to understand why the research is being done and what it will involve. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

### Who can act as a consultee?

Where people cannot take the decision to consent to be involved in a research project, then a consultee must be appointed. A personal consultee is someone unconnected with the research who knows the potential research participant in a personal capacity and is able to advise on the person's wishes or feelings. This can be a friend, family member or court appointee.

# What is the role of the consultee?

The consultee advises the researcher on what the participant's wishes and feelings would be if they were able to consent for themselves and on whether they should take part. The consultee does not give consent, only advice. The responsibility to decide whether the participant should be entered into the research lies ultimately with the researcher. Consultees will be provided with information about the research project and will be given the opportunity to discuss it and their role as consultee. All consultees must be able to understand their role and be willing to undertake it.

### What is the purpose of the study?

In recent years there has been an increase in research on the benefits of music within dementia care. This has ranged from formal interventions provided by music therapists to individuals listening to music. Within care homes, reports suggest that residents can experience insufficient interaction, with many residents having contact time with others as little as 10% of the day.

Lack of interaction could be due to residents with dementia inability to communicate. Formal music therapy sessions have highlighted that music can help residents with dementia develop meaningful interactions, feel less anxious, agitated and depressed, and discover a communication form other than verbal communication. However, due to finances and therapist availability, formal music therapists are not available to all care homes. Music therapists currently provide some therapeutic music skills to staff and families through skill-sharing. There is evidence that many care home staff already use these therapeutic skills without realising. But currently, there is no formal manual that can provide staff with the knowledge and support to use therapeutic music skills within daily routine and music activities. The Person Attuned Musical Interaction in dementia manual (PAMI) aims to be a staff training manual to provide the skills that staff can incorporate into daily routines and interactions with residents. This part of the project is the manual developmental study which will incorporate PAMI into the care homes to gain feedback from staff on the appropriateness and usability of the manual. Feedback collected at this stage will aid revisions to the manual to ensure that it is more appropriate and effective for UK care homes.

#### Why has my relative been chosen?

Your relative is being invited to participate because they are a resident with dementia at a participating care home. We are inviting (9/25) participants like your relative to participate, (3/5) of which are from the same care home.

#### Does my relative have to take part?

We would like you to think very carefully about whether or not this person would have wanted to join the study. If your opinion is that he/she would have decided to take part, you would be given this information sheet to keep and be asked to sign a declaration form indicating your view allowing your relative to participate in the study. If you do decide your relative would like to participate in the study, a video call or in-person meeting will be organised with a member of the research team, to go through the study documents and provide an opportunity to ask any questions. If you still believe your relative will want to participate in the study, you will be asked to sign a consultee deceleration form and to return the consent form to the research team

either in person, electronically or via a pre-paid envelope provided. The research team will then sign the consent form and return a copy of the consent form for you to keep and send a copy to put in your relative's records. If you later decide that he/she no longer wishes to take part, please inform us, and he/she will be withdrawn from the study. You do not need to give a reason, and it will not affect the standard of care your relative receives.

#### What will happen to my relative if they take part?

The study will run for  $(2 \frac{1}{2}, 4 \frac{1}{2})$  months; however, your relative will only be involved in the study for (9/18) weeks.

Your relative will be paired with a member of staff who is also taking part in the study. We aim for this to be the carer who has the most contact with your relative. On the first day, your relative will be asked to complete a demographic questionnaire with assistance from a staff member or relative. The questionnaire will include questions on their age, gender, time at the care home and interest in music. It should only take a few minutes to complete the questionnaire, but the time required may vary between individuals. The amount of assistance required from the staff member or relative will depend on your relative's impairments and abilities. A demographic questionnaire will also be completed for the care home. Staff will also complete the dementia severity scale to collect data on your relative dementia. (The staff member will then complete a series of questionnaires about the resident. The questionnaire will be completed by proxy and will be the staff perception of the residents' experience at the care home.)

Data collected from the questionnaires

Music in dementia- Resident music engagement

QUALIDEM- Resident quality of life

After staff attend training to learn about the PAMI manual and different musical techniques and skills, they will use the music skills and activities with your relative for the next (8/18) weeks. There is no set timing for the use of skills; staff members will determine when they feel most appropriate to use the skills with the residents. Staff will document when the skills are used and how your relative reacted. The skills used will consist of a range of music and musical elements that aid interactions between care staff and residents. There are three main elements of PAMI-Framing, Regulation and Relation. Framing uses music to orient residents to their surroundings and alter the sound environment to correlate with the resident's requirements. Regulation is about using music to alter your relative's emotional state to ensure that they are calm but active. Relation is about using meaningful music to develop meaningful relationships. PAMI

aims to provide each resident with a tailored music intervention adapted to your relative, including tailoring music preference. During this time, your relative is not required to do anything different to their daily routine and behaviour, other than engaging with the staff and activities if they wish. At the end of the study, residents will be asked to complete a post-intervention questionnaire to learn more about their experience using PAMI. Questions will include asking about their enjoyment of the activities and changes in interactions with staff. If the researcher is unable to attend care homes, this will be completed with assistance from a staff member or relative. Otherwise, it will be completed with the researcher. If there is sensitive information your relative wish to include that they do not want staff members to read but require assistance, alternative arrangements can be made to assist with completing the questionnaire. It should approximately 10 minutes to complete the questionnaire, but the time required may vary between individuals.

If your relative has any concerns, questions or issues, they can speak to the researcher in person if the researchers are able to attend the care home under covid guidelines. Otherwise, they can ask the staff member or manager to contact the researchers. If they would like to discuss sensitive topics and do not want the care staff to know, confidential concern forms will be available to write any questions, concerns or issues on. The forms will be accompanied by a pre-paid envelope which can be sent directly to the researchers. Alternatively, your relative can speak to you about the study, and you can contact the researcher on behalf of your relative if this is their wishes.

#### What is PAMI?

PAMI is a care staff training tool for members of staff who have direct daily interactions with individuals with dementia to provide them with musical skills and activities that are generally reserved for music therapy. PAMI aims to improve staff-resident interactions by providing the skills for both staff and residents to have more meaningful interactions that ensure that residents psychological, social and emotional needs are met. PAMI also highlights the use of music and non-verbal communication for residents to communicate and express themselves when verbal language may be impaired.

The manual begins by discussing PAMI's theory, including communication style and research on the benefits of music in care homes. The manual then progresses onto the voice; in this section, staff will learn to become more aware of their voice and the musical elements of the voice that can be changed in relation to resident's behaviour and mood. The manual will then move on to Framing; this section provides the skills needed to use music to cue specific times, events, tasks and people. The section will also explore the sound environment of care homes and how

different sounds can be added or removed to improve the environment for residents. The section on regulation explores how music and musical elements can be altered and adapted to residents' arousal and emotional state to either get residents out of states of apathy or to reduce agitation. The final set of skills is under relation where staff will learn about PAMI music plans, allowing staff to develop a personalised plan of residents' music preferences. In relation, staff will discover how music special to individuals can be used to create conversation and allow individuals to reminisce about their life history. The final section of the manual will provide practical hints and tips for using music in care. This section will also provide a list of suggested songs.

PAMI has been developed based on person-centred approaches. How PAMI is incorporated into routines will be dependent on the care home, the care staff and the needs and preferences of the resident with dementia. Similarly, the type of music activities and songs used should be based on the resident preferences. The PAMI music plan should be tailored to individuals and be created by working with the resident and their relatives. The PAMI activities are not ridged or structured at a specific time or duration. Care staff should use the skills in their routine and tasks when they think is most appropriate and beneficial for the residents.

#### Expenses and payments

Participants will not be paid an inconvenience allowance to participate in the study.

### What are the possible disadvantages or risks of taking part?

We do not anticipate any disadvantages or risk from your relative taking part in the study. PAMI has been developed to make interactions and care home routines smoother and efficient. Therefore we hope that using PAMI will not increase stress or burden, or inconvenience for your relative. There will be no inconvenience as we aim to incorporate PAMI into the current routine without altering tasks or care. When care staff are using PAMI skills, your relative is not required to do anything they do not want to, including engaging with the activities. If there is anything during the study they do not like, they can inform the staff member or researchers, and that task or activity will be stopped immediately. They will be asked to complete two questionnaires, one at the beginning and one at the end, it should only take a few minutes to complete each, but this will be dependent on each individual. If they need any help to complete the questionnaire, they can ask care staff, a relative, or the researcher (if they attend the care home). Your relative may be asked some sensitive questions such as their communication style and interactions with staff. Participants do not have to answer any questions that are sensitive if they do not wish to. The care home and staff members will not know your relatives' answers unless your relative asks staff to help them complete the questionnaire. If your relative requires assistance with the

questionnaire that contains sensitive information, and they do not want staff to see, a relative can assist, or other arrangements can be made to ensure that your relative can feedback their experience.

Your relative's care will not be affected by whether they decided to participate or the answers they provide.

Staff will also be monitoring residents for signs of distress, especially in those that may be unable to communicate distress verbally.

If your relative displays distress while using PAMI, staff members will stop using the manual immediately. Your relatives care at the care home will not be affected by taking part in or by withdrawing from the study.

What are the advantages of taking part?

We cannot promise the study will help your relative, ( but the information we get from this study may help to provide feedback on the current manual, which will aid the revisions.) (but the information we get from this study may help to provide music therapeutic skills to more care homes.) We hope that the PAMI manual may improve resident-staff interactions, which could improve dementia symptoms and quality of life. We also hope that your relative will receive enjoyment from the activities.

What happens when the research study stops?

At the end of the study, the data we have collected will be analysed and used to produce Bryony Waters PhD thesis. (The information that we have collected will also be used to adapt the manual and make adjustments for future studies.) Data collected may also be used for publication or conferences. All participating care homes will receive a summary of the results from the study.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. Staff members can also pass on any concerns to the researchers. The researcher's contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting Patient Advice and Liaison Service, if your relative lives at an NHS care home, who offer confidential advice, support and information on health-related matters for patients and their family. You can find your nearest PALS office on the NHS website (https://www.nhs.uk/) or ask your GP surgery or hospital. If your relative does not live at an NHS care home and remain unhappy and wish to complain formally, you can contact Louise Sabir, contact for the Faculty of Medicine and Health Sciences ethics committee, University of Nottingham (ResearchEthics@nottingham.ac.uk). The complaint process will depend on each care home policies. This will be discussed with the manager, and information will be provided at the beginning of the study.

Will their taking part in this study be kept confidential?

We will follow ethical and legal practice, and all information about your relative will be handled in confidence.

If your relative joins the study, we will use information collected about them during the course of the research. This information will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database at the University of Nottingham. Under UK Data Protection Laws, the University is the Data Controller (legally responsible for the data security), and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after the information and using it properly. Rights to access, change or move your information are limited as we need to manage the information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your relative's rights, we will use the minimum personally – identifiable information possible.

You can find out more about how we use your relative's information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out

correctly. All will have a duty of confidentiality to you as a research participant, and we will do our best to meet this duty.

All information which is collected about your relative during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database. Any information about your relative which leaves the care home will have your relative's name and address removed (anonymised), and a unique code will be used so that they cannot be recognised from it.

Your relative's personal data will be kept for one year after the end of the study. All other data (research data) will be kept securely for seven years. After this time, your relative's data will be disposed of securely. During this time, all precautions will be taken by all those involved to maintain your relative's confidentiality; only members of the research team will have access to their personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies, we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified), but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what your relative tells us is confidential, should they disclose anything or the research team observe a situation that we feel puts them or anyone else at any risk or if their health and/or rights are being infringed, we may feel it necessary to report this to the appropriate persons. Therefore confidentiality will be broken to disclose this to the relevant authority. Participants will be informed if confidentiality has to be broken for this reason.

All identifiable information will be removed from the results prior to analysis and write up. All results will be anonymous, with participants being given pseudo names to protect their identity.

What will happen if I do not want my relative to carry on with the study?

Your relative's participation is voluntary, and you are free to withdraw them at any time, without giving any reason, and without their legal rights or care being affected. If you withdraw your

relative, then the information collected so far cannot be erased, and this information may still be used in the project analysis. To safeguard your relative's rights, we will use the minimum personally-identifiable information possible.

#### What will happen to the results of the study?

After completion of the study, results will be used towards Bryony Waters PhD thesis. Results may also be presented at dementia conferences and in publishable journal articles. The data will also be used to make alterations to the PAMI manual.

#### Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by The Music Therapy Charity.

#### Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participant's interests. This study has been reviewed and given favourable opinion by London-Harrow Research Ethics Committee.

Further information and contact details

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## Researcher- Bryony Waters

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# Appendix 13 PAMI-UK Summary Sheet Manual Evaluation



## Appendix 14 Reflective Session Outline

### **Reflective Sessions**

## (information in red is only present in the manual evaluation study) (information in blue is only present in the manual development study)

- Fortnightly reflective sessions facilitated by one of the research team
- Group sessions but may be 1:1 if the participants schedules do not match
- 40 minutes
- Allow care staff to reflect on their interactions with residents and how they incorporated PAMI into their routine
- Prompt activities to facilitate the reflection
- Opportunity for staff to receive support and guidance on PAMI areas they may be struggling with
- Provide staff with terminology for what they are doing
- Emphasize how they are using the music (not just what music) and why
- Identify areas of need/opportunity to try PAMI

### <u>Session One (manual development study)</u> : Connecting – music care plans

- <u>Intro</u>: It's been a couple weeks since the training about music and how to use music in the care home and while providing care. We hope this has been an opportunity to start exploring music together with your residents, noticing their responses, and connecting with them in this way.
- <u>Check in</u>: How is it going?
  - What have you been doing/trying?
  - What is working well?
  - What is not working well?
- In the training, you reflected on how music was being used in your care home. What do you notice now?
  - How has your awareness of music changed?
  - How has your use of music changed?
  - What songs do you notice residents responding to (positive/negative)?
    - What songs seem most important to residents (individually or in general)?
    - What songs work well in certain situations? Which situations?
  - <u>Reflection Exercise</u>: Think about some interactions you've had with residents in the last couple weeks when you involved music. Write about 2-3 examples:
    - What did you notice that made you think about using music?
    - What impact did you hope music would have in this situation?
    - What music did you involve? How did you involve it?
    - How did it go? What happened?
    - How was this different than the way you used to interact with this resident?
    - How did you feel about this? What are your thoughts on this?
    - What might you do the same or differently next time?
- In the training, you learned about music care plans (Music Plans) and had the opportunity to create one for a resident.
  - How was it for you with creating a music care plan?
    - Did you have trouble answering any of the questions?
    - How did you get the information?

- Were there any challenges (ex. Hard to do, took too much time, didn't understand)?
- Do you have any suggestions/advice from your experience to share with other care staff?
- <u>General Reflection and Q&A</u>:
  - How are you feeling about PAMI and what you've learned so far?
  - What are some successes or challenges you've had with applying what you've learned?
  - $\circ$   $\;$  What are some questions you have, or things you'd like to hear more about?
  - What would be helpful for your next two weeks until we meet again?
- Wrap Up:
  - Great work these past few weeks! It can be difficult to start something new or different. Keep noticing how your efforts are making a difference.
  - Our next refle nctive session will be DATE at TIME. We will plan to talk more about framing, including thinking about the sound environment and how to cue residents about what is going on.
    - Would anyone like a quick recap of this part of the training?
    - Would anyone like to share ideas you already have for exploring these skills?

### Session one (manual evaluation) Check in- getting to know PAMI and your resident

- Admin: Bryony will check in on any documents needed, any distress, permission to record
- Intro: It's been a couple of weeks since the training about music and how to use music in the care homes and while providing care. We hope this has been an opportunity to start exploring music together, with your resident, noticing their responses, and connecting with them in this way.
- Check in: How is it going
  - What have you been doing/trying?
  - What is working well?
  - What is not working well?
- In the training, you reflected on how music was being used in your care home. What do you notice now?
  - How has your awareness of music/your voice changed?
  - How has your use of music/your voice changed?
  - What songs do you notice residents responding to (positive/negative)?
    - What songs seem most important to residents (individually or in general)?
    - What songs work well in certain situations? Which situations?
  - <u>Reflection Exercise</u>: Think about some interactions you've had with residents in the last couple weeks when you involved music. Review your prompt sheet for today:
    - What did you notice that made you think about using music?
    - What impact did you hope music would have in this situation?
    - What music did you involve? How did you involve it?
    - How did it go? What happened?
    - How was this different than the way you used to interact with this resident?
    - How did you feel about this? What are your thoughts on this?
    - What might you do the same or differently next time?

- In the training, you learned about music care plans (Music Plans) and had the opportunity to create one for a resident.
  - How was it for you with creating a music care plan?
    - Did you have trouble answering any of the questions?
    - How did you get the information?
    - Were there any challenges (ex. Hard to do, took too much time, didn't understand)?
    - Do you have any suggestions/advice from your experience to share with other care staff?
- <u>General Reflection and Q&A</u>:
  - How are you feeling about PAMI and what you've learned so far?
  - $\circ$  What are some successes or challenges you've had with applying what you've learned?
  - $\circ$   $\;$  What are some questions you have, or things you'd like to hear more about?
  - What would be helpful for your next two weeks until we meet again?
  - What are your goals for the next few weeks?
- Wrap Up:
  - $\circ$   $\:$  If you haven't already, please take a moment now to complete the MiDAS for this week.
  - Great work these past few weeks! It can be difficult to start something new or different. Keep noticing how your efforts are making a difference.
  - Our next reflective session will be DATE at TIME. We will plan to talk more about framing, including thinking about the sound environment and how to cue residents about what is going on.
    - Would anyone like a quick recap of this part of the training?
    - Would anyone like to share ideas you already have for exploring these skills?

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### <u>Session Two</u>: Framing – sound environment, cuing

- <u>Intro</u>: It's been a couple weeks since our first reflective session together when we talked about using music to connect with residents and music care plans. Since then, we hope you have been able to continue using and exploring music with your residents, as well as using music to cue residents for what is going on and help them feel safe and comfortable in their environment.
- <u>Check in</u>: How is it going?
  - What have you been doing/trying?
  - What is working well?
  - What is not working well?
  - Have you made any changes to your music care plans?
- In the training, we talked about the environment in a care home, especially the sound environment.
  - What do you notice about the sound environment in your care home, and how has this (the sound environment or your awareness) changed since the training?
  - What are some times or some places in your care home when the sound environment is overstimulating or disorienting? When or where is it balanced, clear, or calm?
    - What makes it this way?

- <u>Reflection Exercise</u>: Think about some times in the last couple weeks when you made a point to change the sound environment and/or involve music.
  - What did you notice that suggested a change could be an improvement?
  - What did you change and why?
  - How did it go? What did you observe?
  - How did you feel?
  - Did you notice any responses in other staff?
  - What are some other ideas you have after trying this?
- In the training, we also talked about cuing, or using music specifically to alert residents to what is going to happen next. This helps their routines, and especially transitions, become predictable.
  - $\circ$   $\,$  When does your resident especially have trouble orienting or making transitions?
  - When have you tried using music to cue your resident? How did you use music?
  - What did you do? How did it go?
  - How was this different than without music?
  - $\circ$   $\,$  How was the interaction/experience for you? How did it seem to go for the resident?
  - What might you do the same or differently next time?
  - $\circ$   $\;$  What are some other opportunities to use music for cuing?
- General Reflection and Q&A:
  - $\circ$   $\,$  How are you feeling about PAMI and what you've learned or practiced so far?
  - o Review prompt sheet
  - What are some successes or challenges you've had with applying what you've learned?
  - $\circ$  Were there any surprises?
  - $\circ~$  Do you have any suggestions/advice from your experience to share with other care staff?
  - $_{\odot}$   $\,$  What are some questions you have, or things you'd like to hear more about?
  - $_{\odot}$   $\,$  What would be helpful for your next two weeks until we meet again?
  - What are your goals for the next week?
- Wrap Up:
  - If you haven't already please take a moment now to complete the MIDAS for this week
  - Great work these past few weeks! Hopefully you are gaining some confidence and ideas for how music can be used with your residents and in your care home.
  - Our next reflective session will be DATE at TIME. We will plan to talk more about balancing, including paying attention to arousal and how we use our voice.
    - Would anyone like a quick recap of this part of the training?
    - Would anyone like to share ideas you already have for exploring these skills?

### <u>Session Three</u>: Balancing – arousal, the voice, attunement

• <u>Intro</u>: It's been a couple weeks since our second reflective session together, and we are now well into PAMI. We've had a chance to reflect further on music care plans,

sound environments, cuing, and using music in interactions. Today is our last reflective session together.

- <u>Check in</u>: How is it going?
  - What have you been doing/trying?
  - What is working well?
  - What is not working well?
  - Have you made any changes to when/how you are using your PAMI skills?
- In the training, we talked about balancing, or helping to regulate a resident's emotions and level of arousal.
  - Can you share about a time when a resident seemed to be overstimulated or agitated and in need of calming?
  - Can you share about a time when a resident seemed lethargic or apathetic and needed stimulation or engagement?
  - $\circ$   $\,$  How do you regulate yourself (ex. center yourself) when working with a resident?
  - <u>Reflection Exercise</u>: Think about some times in the last few weeks when you used music to help with regulation and balance.
    - When did you use music (ex. waking, bedtime, movement, transitions)?
    - What song or music did you use?
    - How did you make the music sound? What musical elements were you thinking about?
    - How did it go? What did you observe?
    - How did you feel?
    - What are some other ideas you have after trying this?
- We also talked about using your voice to help balance or regulate. This could involve humming or singing while you modulate or adjust your voice according to the resident and the situation.
  - $\circ$  What is something new or different you have tried with your voice since the training?
  - How did it go? What did you observe?
  - How did you feel about it? Would you try it again?
- We talk about "attunement" as a way of connecting with people by being present to and with their experience and emotions. You might think of this as "tuning to their station."
  - How have you attuned to a resident?
  - What do you noticed when you take time to connect first? How do you know when you are attuning?
  - How can/has music helped you attune to a resident?
- In music therapy, we talk about a concept called the "iso principle." This refers to first meeting or matching a person when trying to change their emotional or energy state. So if someone is really agitated, I might first sing or play a fast, snappy tune before slowing it down. Or if a resident doesn't seem very alert or interested, I might start with a relaxed song before moving to something more energetic. The main point of this is that if we want to help make a change in someone, we first have to "click" with them or "attune" to them and then draw them along with the change. Otherwise, if we start with a song, for example, that feels really different from where they are feeling at the moment, it is hard for them to relate to and may even make them more agitated.

- o Can you think of a time when you decided to use music during an interaction with a resident, but it didn't go the way you expected?
- Can you think of a time when you decided to music with a resident, and it 0 seemed to create a real connection between you?
- General Reflection and Q&A:
  - How are you feeling about PAMI and everything you've learned and explored in your own work?
  - o Review prompt sheet
  - What are some successes or challenges you've had with applying what you've 0 learned?
  - Do you have any suggestions/advice from your experience to share with other care staff?
  - What has been the most helpful part of PAMI training and practice? The least helpful?
  - What are your goals for the next few weeks?
- Wrap Up:
- If you haven't already, please take a moment now to complete the MIDAS for this week
  - o Great work with your PAMI skills so far! We hope you will continue to use and benefit from these skills in your work with care home residents.
  - Our next reflective session will be DATE at TIME. We will plan to talk more 0 about connecting, including attunement and reminiscecing
    - Would anyone like a quick recap of this part of the training?
    - . Would anyone like to share ideas you already have for exploring these skills?
  - This was our last reflective session together. However, we will be doing one-0
    - on-one interviews with you to hear more about your experience with PAMI. Schedule interviews

#### Session Four: Connecting – attunement, holding, validation, reminiscence

- Intro: It's been a couple weeks since our last reflective session together, and we are now well into PAMI. We've had a chance to review and reflect elements related to framing and balancing. Today we'll review some more elements of PAMI related to connecting.
- Check in: How is it going?
  - What have you been doing/trying?
  - What is working well? 0
  - What is not working well?
  - Have you made any changes to when/how you are using your PAMI skills?
- We talk about "attunement" as a way of connecting with people by being present to and with their experience and emotions. You might think of this as "tuning to their station."
  - How have you attuned to a resident?
  - What do you noticed when you take time to connect first? How do you know when you are attuning?
  - How can/has music helped you attune to a resident?
- In music therapy, we talk about a concept called the "iso principle." This refers to first meeting or matching a person when trying to change their emotional or energy state. So if someone is really agitated, I might first sing or play a fast, snappy tune before slowing it down. Or if a

resident doesn't seem very alert or interested, I might start with a relaxed song before moving to something more energetic. The main point of this is that if we want to help make a change in someone, we first have to "click" with them – or "attune" to them – and then draw them along with the change. Otherwise, if we start with a song, for example, that feels really different from where they are feeling at the moment, it is hard for them to relate to and may even make them more agitated.

- Can you think of a time when you decided to use music during an interaction with a resident, but it didn't go the way you expected?
- Can you think of a time when you decided to music with a resident, and it seemed to create a real connection between you?
- "Holding" describes just sharing a moment with someone and being present to them without being distracted or trying to accomplish a task. Holding involves tuning into the other person and helps to make them feel safe and understood.
  - Have you experienced any shared moments with your resident? What were they like? What helped you to connect in the moment?
  - How can/has music helped with this?
- <u>General Reflection and Q&A</u>:
  - How are you feeling about PAMI and everything you've learned and explored in your own work?
  - Review of prompt sheet.
  - What are some successes or challenges you've had with applying what you've learned?
  - Do you have any suggestions/advice from your experience to share with other care staff?
  - What has been the most helpful part of PAMI training and practice? The least helpful?
  - What are your goals for the next few weeks?
- <u>Wrap Up</u>:
  - $\circ$   $\:$  If you haven't already, please take a moment now to complete the MiDAS for this week.
  - Great work with your PAMI skills so far! We hope you will continue to use and benefit from these skills in your work with care home residents.
  - Our next reflective session will be DATE at TIME.

### Sessions 5-9: Review and Supervision

- <u>Intro</u>: It's been a couple weeks since our last reflective session together.
- <u>Check in</u>: How is it going?
  - What have you been doing/trying?
  - What is working well?
  - What is not working well?
  - Have you made any changes to when/how you are using your PAMI skills?
- <u>General Reflection and Q&A</u>:
  - How are you feeling about PAMI and everything you've learned and explored in your own work?
  - Review of prompt sheet.
  - $\circ$  What are some successes or challenges you've had with applying what you've learned?

- Are there any areas of resident care or interactions that have been challenging or where you think PAMI could be helpful?
- Do you have any suggestions/advice from your experience to share with other care staff?
- What has been the most helpful part of PAMI training and practice? The least helpful?
- Are there any PAMI skills/elements you'd like to review or discuss?
- What are your goals for the next few weeks?
- <u>Wrap Up</u>:
  - $\circ$  ~ If you haven't already, please take a moment now to complete the MiDAS for this week.
  - Great work with your PAMI skills! We hope you will continue to use and benefit from these skills in your work with care home residents.
  - Our next reflective session will be DATE at TIME.
  - (Session 9) This was our last reflective session together. However, we will be doing oneon-one interviews with you to hear more about your experience with PAMI.
    - Schedule interviews

## Appendix 15 Interview Topic Guide

## <u>Topic guide</u>

#### (Final version 1.0:11/03/2021)

(Information only in manual evalaution study)

#### (Information only in manual field-testing study)

#### IRAS Project ID: 293613

Title of Study: Development and evaluation of the Person Attuned Musical Interaction in Dementia Manual UK version (PAMI-UK)

Name of Chief Investigator: Dr Orii McDermott

Local Researcher(s): Bryony Waters & Martin Orrell

#### The PAMI Manual

- Overall thoughts on the PAMI manual.
- Did the manual provide you with the required knowledge and skills to use PAMI ?
- Thoughts on the manual layout.
- How did you find navigating the manual to find the information you needed?
- Thoughts on the manual's language. Is the content clear and understandable?
- Thoughts on the usability of the PAMI manual. Is it user-friendly?
- Was the manual suitable for its intended purpose and for care staff?
- Any suggested changes to the manual to make it more appropriate.

### The PAMI training

- Overall thoughts on the training.
- How do you feel the PAMI training went for you? Did you feel that it covered all the areas you required?

- Thoughts on training layout.
- Thoughts on online training. Did the online training affect your experience?
- What elements of the training did you find useful?
- What elements of the training did you not find helpful?
- How did you find the length of time required to complete the training?
- Any suggestions for changing the training.

### ΡΑΜΙ

- Residents reaction to PAMI.
- Impact of PAMI on yourself and residents.
- PAMI's impact on interactions and social engagement.
- Experience of incorporating PAMI into daily routines.
- How did the addition of PAMI affect your daily routine?
- Did you feel that anything had changed about your routine since starting PAMI?
- What elements of PAMI did you find easiest to implement?
- What elements of PAMI did you find hardest to implement?
- What elements of PAMI have you found most successful?
- How has your views on the use of music in care changed after using PAMI?
- Do you believe you will continue using the skills you have learnt?
- Factors and barriers affecting the implementation of PAMI.
- Ability to implement PAMI long-term.

## **Reflective sessions**

- Appropriateness of reflective sessions.
- Ease ability to attend sessions.
- Usefulness of sessions.
- Any changes to reflective sessions.

## The study

- The appropriateness of the study design
- The suitability of diary entries
- The availability to complete training and reflective sessions
- Changes to the study design to make it more suitable for care staff

Any other questions

# Appendix 16 Manual Evaluation Reflective Session Prompt Sheets

#### **Reflective Session Prompt sheet**

#### Reflective session 1

Care home \_\_\_\_\_

Participants \_\_\_\_\_ Date \_\_\_\_\_

Each week think about one of the interactions you have had with your resident since our last meeting and make a few notes using the prompts below. Bring your notes with you to the next reflective session and we will explore the interaction together.

- Did you feel that this was a good interaction?
- Did the interaction contain any of the PAMI skills? If so which ones?
- How did the resident respond to the interaction?
- How did the interaction make you feel?
- Did anything go wrong with the interactions?
- Is there anything that you would have changed with the interaction?

Describe in detail an interaction you had with your resident over the last fortnight using the prompts provided.

Goal for interactions over the next fortnight

Any other notes

# Appendix 17 Manual Evaluation Recap Sheet

# **PAMI** Recap Sheet

## The voice

The voice focuses on the musical elements that contribute to our voices.

- Our voice consists of musical properties similar to music such as tone, pitch, tempo and timbre
- If we can recognise the musical properties, we can alter them in different situations or with different individuals to improve the interaction.

## Framing

Framing focuses on assessing and altering the care home environment in relation to sounds.

- Aim to create a safe environment for residents by creating predictability and recognition.
- Creating a safe space
  - Meet the individual on their level
  - $\circ$   $\;$  Provide time for the individual to respond in their own time
  - o Check the individuals mood and try to align to this
  - Use non-verbal communication such as touch, eye contact and smiling
  - o Remove unnecessary noises in the environment
  - Aim to enter the individuals reality
  - o Observe and listen to the individual

## Cueing

- Using the same piece of music to signal a specific task or time of day
- You can sign the instructions of a task
- Curing can orientate the individual

## Sound environment

- Hi-fi Fidelity sound environment is idea for care homes as the sound environment is cleaner and it is easier to separate individual sounds
- Assessing the sound environment of the care home can all for sounds to b added or removed to provide a more hi-fi environment

## Balancing

Balancing focuses on the residents and staffs arousal and emotional state.

- Residents can experience states of high (agitation, anxiety, restlessness) or low (apathy, inactivity) arousal throughout the day
- High and low arousal makes interactions difficult, a more balanced arousal will allow for more fluid and natural interactions to occur

- Aim to a tune to the other persons arousal state before attempting to alter the state
- Before entering an interaction check your own emotions and arousal state, this could affect the interaction
- You can regulate arousal using your voice by altering the musical properties of the voice and body use as tempo, rhythm, timbre, volume, pitch and timing.
- Regulating using the voice and body
  - High arousal- soothing voice, slower tempo, smooth rocking movements, a certain distance and non-demanding attitude
  - $\circ$   $% \left( {{\rm{Low}}} \right)$  Low arousal- vivid tempo, piercing voice, quick movements, touch and emotionality
- You can use music to regulate arousal, find music that first matches the state of the individual before slowing altering the music to either increase or decrease arousal.
- When an individual is in a high state of arousal you can sing a tune and gradually regulate down by slowing the tempo and taking pauses for deep breaths in between each stanza

## Connecting

Connecting focuses on using music to create meaningful interactions and to connect with the resident.

- Ensure that all music care incorporated into an individual's care is person-cantered. Tailor the activities and type of music used to the individuals' preferences.
- Recognise residents use of non-verbal communication (these may be subtle cues), and attempt to respond to them to give them meaning and context
- The PAMI care planning can ensure that music interactions are individualised to the individual
- **Validation** The recognition, understanding and acceptance of a person's beliefs, thoughts, emotions and behaviours
- **Holding** Being present Recognise and understanding an individual's emotions and provide a sense of safety.
- Attunement- Being present to and with another person's experience and emotions
- Aim to attune into the individuals memories and internal resources
- **Centring for holding** if feeling stressed before entering an interaction take a few minutes to ground yourself to the earth and take deep breaths
- Use meaningful music to discover the individuals life history and create conversations to reminisce
- Group music reminiscence can lead to conversations between residents and create a sense of group membership

## Appendix 18 Resident Experience Form

**Residents experience of PAMI** 

(Final version 1.0:11/03/2021)

IRAS Project ID: 293613

Title of Study: Development and evaluation of the Person Attuned Musical Interaction in Dementia Manual UK version (PAMI-UK)

Name of Chief Investigator: Dr Orii McDermott Local Researcher(s): Bryony Waters & Martin Orrell

Have you enjoyed the music activities you have taken part in over the last couple of weeks?

What was your favourite activity?

Was there any activity you didn't like?

Did you feel that the music used was appropriate for you?

Is there any thing you would have liked to be different?

Have you found you conversations with staff have been different recently?

Have you enjoyed taking part in the research?

Any additional comments about the residents experience of PAMI or the study can be added below.

# Appendix 19 Diary Entries

#### Person Attuned Musical Interaction (PAMI) manual diary entries (manual evaluation study)

(Final version 1.0: 11.03.2021)

IRAS Project ID: 293613

Title of Study: Development and evaluation of the Person Attuned Musical Interaction in Dementia Manual UK version (PAMI-UK)

Name of Chief Investigator: Dr Orii McDermott

Local Researcher(s): Bryony Waters & Martin Orrell

Dyad code

Start of study date

Identification code

Date & Time	PAMI section Framing/Balancing/Connecting	PAMI skill used and time spent on skill	Residents reaction	Effects on interaction	Any other comments
14/01/2021 7:30am	Framing/ Balancing	When I went in to wake CM up, I sang, 'Oh, what a beautiful morning'. I begin humming first until she is more awake, and then we sing together. 25 minutes	CM is more willing to wake up. She is in a more positive mood and is more willing to let carers assist with personal care.	When CM wakes up, she wants to have a hug from carers and connect through handholding before starting personal care. I feel that we have a closer bond. Spend time in the morning laughing together.	Using the skill in the morning has led to a more relaxing morning for both myself and the resident. We can complete the task quicker without CM getting agitated.

Date & Time	PAMI section Framing/Regulation/Relation	PAMI skill used and time spent of skill	Residents reaction	Effects on interaction	Any other comments